Couple Relationships and Emotional Well-being After Severe Traumatic Brain Injury

Thesis

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Couple Relationships and Emotional Well-being After Severe Traumatic Brain Injury

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Submitted in partial fulfilment of the requirements for the degree of
DOCTORATE OF CLINICAL PSYCHOLOGY

CLINICAL PSYCHOLOGY
SALOMONS CENTRE
ACCREDITED INSTITUTION OF THE OPEN UNIVERSITY

Date of award: 11th September 1996

SEPTEMBER 1996

The information in this study preserves anonymity of the participants and names have been changed to maintain confidentiality.

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ACKNOWLEDGEMENTS

My biggest and sincerest thanks go to the couples, particularly the women, who generously offered their time and energy to take part in the study. Also, for their hospitality in accommodating me in their homes, so that I could carry out the interviews, was much appreciated. Their help made this study possible.

Many thanks to Mike Oddy for supervision; and to Margie Callanan, Elizabeth Francis and Graham Dunn for their valuable time at various stages of the research. Also to my dear friend and colleague, Brian Solts, for his guidance, patience and support.

Thanks to the co-ordinators of various branches of Headway: Pam Monro, Ann Cummings, Ann Stevenson, Margaret Bray, and Pam Holloway, without whom I would not have been able to access participants. Also to Linda Thompson, Julia Nolan and Yolande Ironside for their help with administrative tasks.

Lastly and crucially to: my mother for her invaluable personal support, and for supplying me with a car to carry out the interviews after my own died! And to Sara for her uplifting love and endless encouragement.

ABSTRACT

A quantitative method complemented by a qualitative approach was used to explore couple relationships after traumatic brain injury (TBI). Eighteen couples where the male had sustained a severe head injury, who were in stable relationships before the injury, and still together at the time of the study, took part. The study focused on the reports and experiences of the women, between one and seven years after the injury; data was gathered in personal interviews. Significant differences were found between: the quality of the relationship before and after the injury, in the direction of deterioration of the relationship after injury; aspects of sexual satisfaction before and after injury, again in the direction of deterioration. Significant differences were also found between head injured mens' and womens' reports of aspects of marital state, with women reporting more problems than men. The more sexually coercive men were perceive to be, the lower the womens' ratings of sexual satisfaction; the less welcome head-injured mens' sexual advances were, the more the women partners avoided sexual contact.

The qualitative component indicates that the women in the sample had coped with multiple losses and acquired extra responsibilities, leading to a high level of emotional distress and denial of feelings; many were ambivalent and confused about their partners' feelings for them. Committment and companionship were cited as positive aspects of the relationship. The future was seen either with little change or not anticipated at all. Little formal support had been offered and most women said that thay would have liked individual help from services. Clinical implications and directions for future research are discussed.

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CHAPTER ONE

INTRODUCTION

Over the past decade increasing attention has been paid to psychosocial factors following traumatic brain injury (TBI) and particularly to the difficulties of the families of head-injured survivors (see Brooks, 1991 for a review). After the acute phase of recovery following TBI, it is generally a member of the close family or significant other who assumes the primary caring role for the survivor. Studies have tried to address the question of whether wives or mothers of head-injured men experience greater emotional distress in the role of carers and there is disagreement about this in the literature. Maus-Clum and Ryan (1981) found wives reported higher levels of stress than mothers of adult children who had sustained a head injury. According to Florian and Katz (1991) evidence suggests that wives of head-injured men experience more psychological distress than mothers: it has been suggested that they have more difficulty in accepting the frequent childish behaviour of the injured person, whereas parents may find it easier to adjust to. This is because the childish dependency, so often a consequence of severe head injury, has previously been a component of the mother/child relationship; this is not generally accepted as a healthy aspect of marital relationships (Florian and Katz, 1991). However, Livingstone, Brooks and Bond (1985) did not find evidence to support differences in wives' and mothers' psychological reactions to various situations after TBI, although they did find some evidence to suggest that wives sustained a poorer outcome. Brooks, Campsie, Symington, Beattie and McKinlay (1987) suggest that it is the nature of the burden experienced that is different rather than the amount of burden being different.

Although studies have explored the emotional well-being of female partners who are carers there has been less research to identify specifically what is difficult about living with a head-injured partner and subsequently, why there may be difficulties in the couple's

relationship. Literature on marital state and how people experience intimate relationships post-injury is particularly sparse. Furthermore, apart from speculative comment, there has been little empirical research in the UK exploring the nature of sexual relationships after TBI. The present study is therefore concerned with exploring these areas focusing on female partners of men who have sustained severe head injuries.

1.1 Services and resources for people with TBI and their families

Prevalence and incidence reports are variable depending on definitions of severity and whether the sample was a hospital population or not. Tennant (1995) offers a comprehensive discussion of the methodological issues related to epidemiology. Although fewer than 10 per cent of head trauma survivors are severely injured, Lezak (1995) points out that they present a major and growing social concern in that their rehabilitation needs are so great and so costly as few return to fully independent living. The challenges presented to the health services are outlined by Chamberlain (1995). She cites the term 'silent epidemic' as being used to describe head injury and says it is at least 35 times more common than spinal injuries 'and yet the services for it are underdeveloped ...' (p.4). The number of survivors of severe head injuries has recently increased due to both changes in medical knowledge, and the increased use of motor vehicles. Another concern is the burden of the long-term effects which impact upon the head-injured person and their family that are life long: average time of survival is 50 years.

Head injury rehabilitation services currently occupy a scant place in NHS resources; they are not categorised as a separate area of need from, say, learning disabilities or mental health, despite the fact that their needs are very different. Rehabilitation services for

survivors and their families are therefore scarce. Although research has tried to understand the impact of head injury on families, there has been little research, particularly in this country, to try to understand couples' relationships after an injury. The service implications in terms of providing services for couples have received little consideration.

1.2 Definition and outcome of acceleration/deceleration head injury

In head injuries sustained through accidents, the injury to the brain can be described in terms of the damage being caused by the brain accelerating or decelerating within the skull. The energy of the impact to the skull is dissipated within the head resulting in twisting and oscillating movements of the brain. Some structures may be sheered and bruised. Compression to the brain by swelling of damaged surrounding tissue and ischaemia produce further more diffuse damage (Neumann, 1995).

The Glasgow Coma Scale (GLS) (Jennet and Bond, 1975) is a measurement of depth of coma and is used to predict the outcome of TBI, although coma duration alone is a good predictor of outcome for more severe injuries (Lezak, 1995). Another commonly used index of severity of injury is post-traumatic amnesia (PTA). Severity of head trauma usually predicts behavioural and neuropsychological outcomes (Kreutzer, Devany, Myers and Marvitz, 1991, in Lezak, 1995).

Lezak (1995) suggests that the most serious effects of head trauma involve personal and social competence, more so than even cognitive impairment and cautions that when discussing severity ratings and outcome predictions it is as important to note the discrepancies as it is to report general trends: those people whose injuries seem mild, as

measured by accepted methods, may have relatively poor outcomes, and conversely, others who may have been classified as moderately to severely injured can enjoy surprisingly good outcomes. It is suggested that variables other than individual differences, the family, services and the wider system, may mediate recovery.

1.2.1 Effects of severity of injury on family outcome

Injury characteristics have been explored in terms of severity and time since injury on family outcome (Brooks *et al.*, 1987). Serio, Kreutzer, and Gervasio (1995), citing Thomsen (1974;1984) explain that this is likely to be related to the scarce availability of professional and community services after the acute stage of recovery. However, as they point out, the outcomes of studies are limited by methodological flaws or inconsistencies in classification and restricted samples. It is suggested here that the lack of support allows carers' stress to go unchallenged, rather than the lack of support causes stress; it is likely that there is a need for professional input in the longer term. Some studies suggest that initial severity indices are not predictive of long term outcome for relatives' well-being (Oddy, Humphrey, and Uttley, 1978; McKinlay, Brooks, Bond, Martinage and Marshall, 1981), but other variables might help to explain this: at a time which is inherently stressful the increased levels of reported stress could be related to the injured person being away from home. The current study includes exploration of emotional well-being of spouses within a specific time period post-injury, also inviting comments about services from participants.

1.3 Personality, behaviour and psychosocial changes after severe TBI and the consequences for families

Following the acute phase of recovery there may be an expectation by relatives that survival means full recovery (Novack and Richards, 1991), but frustration can build up if the survivor does not recover as quickly as relatives had hoped or expected. In the later stages of recovery spouses and relatives begin to realise that the person will not return to their previous state; their recognition of personality changes appears to increase over time (Brooks and McKinlay, 1983). Adjustment to the change has been described in terms of a loss model by Lezak (1982) often taking the form of resignation rather than acceptance.

The behavioural effects of all brain lesions depend on a variety of factors, such as severity, age, site of lesions, and premorbid personality characteristics, yet the similarities in behavioural patterns of those with closed head injuries tend to outweigh the individual differences (Lezak, 1995). The most common and fundamental effects of severe head injury are to higher functions and the consequences can be physical, cognitive, and personality/emotional changes.

1.3.1 Physical limitations

These can include sensory disturbances, paresis or paralysis, and apraxia or ataxia. (Imes, 1983). Functional deficits in daily living activities can reflect these physical limitations or, more frequently, be the result of cognitive and behavioural problems, such as lethargy, impulsivity, poor memory, and problems with concentration and attention. Speech problems too can be the result of either cognitive or physical limitations.

1.3.2 Cognitive changes

Each survivor presents unique characteristics; some functions continue at premorbid levels. Attention deficits and memory impairments are extremely common as are those which interfere with the ability to use knowledge and skills fluently (Walsh, 1985, in Lezak, 1995). Following TBI there is often reduced awareness of deficits without which survivors may not be motivated to participate in rehabilitation nor able to monitor themselves effectively (Crosson, Barco, Velezo, Bolesta, Cooper, Werts and Brobeck, 1989). The capacity for self-determination and self-control depend on self-awareness (Lezak, 1978); if self-awareness is compromised then empathy and insight is impaired (Crosson *et al.*, 1989). However, head injured survivors often appear untroubled by this and may attempt to resume previous work or carry out tasks that are beyond their capabilities. Cognitive changes resulting in inflexible concrete thinking can also be particularly difficult for a partner or relative to live with, as are irritability and poor control of temper.

1.3.3 Personality changes

This can include a wide range of emotional and behavioural problems. As with many cognitive consequences of head injury, the personality changes tend to be associated with injuries where the frontal lobe has suffered damage. Often these changes can be quite subtle and not immediately obvious even to close friends or family who do not live with the head-injured person (Oddy, 1995). Even subtle changes can make the person seem like a stranger inhabiting the body of someone they knew. So, for partners/families the person for whom they are caring is often perceived as a stranger (Oddy, 1995) and they are challenged with experiencing profound change in the nature of their personal

relationship with the head-injured person. The spouse/relative is in the position of not only having to grieve the loss of the person they loved, but additionally learning to live with a stranger.

1.3.4 Emotional problems

The emotional changes post head injury tend to involve either exaggeration or dulling of affective experience and responses (Brooks and McKinlay, 1983). While some emotional reactions are due to organic changes in brain functioning, Gainotti (1993) suggests there is likely to be differing amounts of organic and psychogenic influences in different individuals at different times. Social isolation is a common result of these emotional changes; the cognitive difficulties experienced can prevent the injured person socialising effectively (Fordyce, Roueche and Prigatano, 1983) so impacting on social life and work (Thomsen, 1984; Weddell, Oddy and Jenkins, 1980). Loss of confidence and subsequent social withdrawal can result in loneliness and depression for many moderately and severely injured survivors (Oddy, Humphrey and Uttley, 1980) with increased dependency on their family for social contact and support (Kinsella, Ford and Moran, 1989); families themselves become increasingly socially isolated (Florian, Katz and Lahav, 1989).

1.3.5 Summary

Head injury exposes families to a unique complex of stressors (Oddy, Humphrey and Uttley, 1978). The long-term consequences of head injury can result in numerous problems for carers. Disabilities create huge emotional and financial burdens on families: changes in cognition and emotional responsiveness may alter the core characteristics of the person (Oddy, 1995). Studies have explored the relationship between patients'

cognitive and personality changes and family adjustment. On scales assessing expression of affection and total marital adjustment (based on spouse self-reports), Peters, Stanbrook, Moore, Zubek, Dubo and Blumenschein's findings (1992) indicate that couples in a severe TBI group showed less expression of affection and less marital adjustment than couples in a moderate TBI group, who in turn showed less than a spinal cord injury group.

1.4 Problems faced by couples following TBI.

From a systems perspective, Miatz and Sachs (1995) posit that a person's power and authority are a function of their role in the system. An understanding of roles, role relationships, and the distribution of power and authority within a system is critical to understanding the response to trauma (Miatz and Sachs, 1995). Relationship roles often change after a severe brain injury and destabilise the system.

Couple relationships also exist within a system. Clulow and Mattinson (1989) explain that love of another person as a complement to the self is one way in which a relationship can function. Such complementarity could take the following form. 'The calmness, even dullness, of one partner may be useful and containing to an excitable other, just as the more emotive responses of the latter may engage and bring spontaneity into an otherwise stable and ordered life' (p.53). Similarly, complementarity exists in couples where a dominant person complements the characteristics of a more passive person.

TBI suddenly compromises couples' abilities to enact roles and disrupts the balance of power between them; this destabilises the system. Butler and Satz (1988) explain that the balances developed by a couple can be shattered, resulting in disharmony and maladjust-

ment. In particular, previously dominant males may become dependent upon their wives. For example, a man who perceived his role as the family provider may have difficulty in accepting a diminished role after TBI (Cavallo and Saucedo, 1995). Expression of dependency needs and fear of abandonment amount to marital vulnerability, contend Kravetz, Gross, Weiler, Ben-Yakar, Tadir and Stern (1995), a concept they explored in relation to traumatic brain injury (TBI): in fact their findings found that men with TBI *and* their wives exhibited a decrease in self-esteem and an increase in conflict, suggesting that the entire system is destabilised.

When wives of paraplegics were compared to wives of head injured men, the latter experienced the following: greater role changes in their marital relationships; more dislike of physical contact with their husbands; the husband's disability was found to be more of a social handicap which led to greater loss of contact with friends; significantly more symptoms of low mood (Rosenthal and Najenson, 1976). In fact, Rosenthal and Najenson (1976) hypothesise that 'good adjustment involves a change in the wife's role from that of an equal partner to the role of mother or surrogate nurse' (p. 885). Findings are indicative of a wife/partner's change in roles following her husband/partner's head injury: the implication being that they had lost their previous position in the relationship and they were no longer in what might have been a give and take relationship, but replaced by one in which their husband is dependent.

Gleckman and Brill (1995) contend that a re-evaluation of roles demands open lines of communication and the capacity to cope with transitions. Communication skills place demands on cognitive ability and qualities of empathy and reasoning which may be

especially difficult for a head-injured survivor. This then requires recognition that roles need to change. Because of their reduced insight and lack of awareness of their limitations, the head-injured person may not appreciate the need to adopt a different role; this is likely to have implications for the health of the couple's relationship.

Horowitz and Shindelman (1983) explored influences of past reciprocity on current caregiving. Anecdotal evidence based on reports from senior clinicians working in head injury services suggest that changes in the reciprocity in relationships after head injury may affect the mutual emotional support, satisfaction and trust that is often expected from a partner. This may be a component that is not available to partners of survivors. The current study examines the differences in marital state, as perceived by wives, before and after injury, in particular, the influence of a perceived dependency on ratings of marital state is investigated. Crucial to the understanding of the relationship change is what aspects the female partners feel has changed the most and their views of the concomitant role change in the relationship? The current study addresses this gap.

1.4.1 Perceptions of partners

In intimate or emotionally close relationships the changes described are likely to make a great impact. Maus-Clum and Ryan (1981) found 32 per cent of wives reported feeling married to a stranger, almost half reported they were 'married but did not have a husband', and felt trapped. Lezak (1978) suggests that likely strains on the marital relationship post-TBI go beyond the emotional burden of caring and may impose social isolation on the non-injured partner. She also speculates that they cannot easily seek out other partners because they are still married, though there is little research to indicate

whether they contemplate this. The current study attempts to gain insight into these areas and explores which aspects of the relationship are viewed by wives as positive and how they see the future.

1.4.2 Sexual relationships

Sexual relationships can also become a focus of tension and conflict although there is a paucity of literature in the area of TBI and sexual relationships. Lezak (1976) posits that the secondary effects of brain damage following TBI on personality and behaviour, such as loss of empathy, clumsiness and tactlessness may lead to insensitive attempts at intimate behaviour, inappropriate touching, aggression or changes in sensitivity. Lezak (1976, 1978) suggests that, for these reasons, the women partners of men post-TBI seldom have their psychosexual and affectional needs satisfied. No empirical study has followed up this clinical observation.

The studies that have been carried out focus mostly on the head injured male without incorporating partner's reports and have small sample sizes of between four and twenty-one (Kreutzer and Zasler, 1989; Kosteljanetz, 1991, in Garden, 1991; Boller, 1982, in Garden, 1991). Zasler (1991) surmises that sexual dysfunction, mostly in the area of decreased interest, is common in head injured men and acknowledges that their responses may correlate poorly with objective criteria and partner's responses. Although physical problems may be an issue, psychogenic sexual dysfunction can be complicated by the depression, altered body-image and lack of confidence in the head-injured population. In a postal survey exploring sexual satisfaction, O'Carroll, Woodrow and Maroun (1991) found 50 per cent of their sample of 36 head-injured men and nine per cent of their sample

of 17 women partners would have been classified as being in the 'dysfunctional sexual relationship' range.

According to the literature on relationships the failure to have psychosexual needs met may jeopardise a relationship (Dryden, 1985). However, Hartman (1980) and Patton and Warind (1984) report that a satisfying sexual relationship is not the only necessary factor for an acceptable partnership. Citing Rosenbaum and Najenson's (1976) study, Florian, Katz and Lahav (1989) suggest that in some partnerships, poor sexual relationships can be compensated for by intimacy and togetherness. But they note that after TBI the problems in sexual relationships may be a function of the changes in personality and so intimacy and togetherness may not be available from the injured partner as compensation for the spouse. The blunting and loss of emotional feelings which can result from a head injury (which in turn can influence whether a person is motivated to engage in shared activities) can have critical implications for the viability of an intimate relationship. However, Garden, Bontke and Hoffman's (1990) survey of couples where the male partner had mild head injury found that 53 per cent of spouses reported overall satisfaction with sexual adjustment although less frequent intercourse took place post-TBI. This meant that nearly half of the sample were not satisfied where only mild head injuries had happened. This could indicate that for couples where head injury has been severe there may be even less satisfaction.

Lezak (1978) reports that many patients either have no sex drive or exhibit increased sexual interest. She speculates that some men post TBI who cannot perform sexually may blame their partners and may consequently be more insistent sexually: she suggests that

a sexually uninterested male partner may be easier to live with. Maus-Clum and Ryan (1981) addressed changes in the marital relationship: 47 per cent of respondents reported the person with TBI as either preoccupied with or disinterested in sex, although the research did not provide further data about this.

The extent to which female partners are still physically attracted to their partners is another relevant variable. Studies of couple relationships where men have suffered spinal injuries indicate that relationship which have begun since injury are more successful than those which began before the injury (Crewe and Krause, 1988). It is suggested that changes in the injured person after TBI could influence the level of attraction that spouses have for their husbands. Furthermore, if a carer is performing tasks of a personal nature for another person, then that person may become less sexually attractive to them. Reasons for this are likely to be related to the parental nature of such tasks which are not compatible with sexual relationships.

In the clinical setting, anecdotal evidence from staff groups and other clinicians indicate that marital state or impact of TBI on intimate relationships is not routinely explored. Findings from an American study exploring staff attitudes and behaviour stated that 79 per cent of 129 rehabilitation professions believed sexual adjustment was as important as any other area of rehabilitation, yet only nine per cent indicated that they felt comfortable discussing the topic. Fifty-one per cent that they discussed it if the client asked about it and 41 percent said they felt uncomfortable due to lack of information or experience (Ducharme and Gill, 1990). Generally, it is left to service users to raise the subject. However, this assumes and requires that they feel able to do so which may or may not be

the case. The present study endeavours to explore womens' views about their sexual relationships since their husbands' injury.

1.4.3 Divorce and separation

Severe head injury reduces the quality of life for survivors and that of people close to them. Oddy (1995) states that the question often arises as to whether the spouse can continue living with the head-injured person. Given the enormous strains the question as to what keeps couples together is an interesting one. Amongst couples in stable relationships, the divorce and separation rates appear high but rates described in studies are not consistent. In a 15 year follow up study of nine couples, Thomsen (1984) found that only two remained married; both of these were childless. Oddy (1995) suggests that perhaps it is the presence of children that helps to resolve the dilemma for the uninjured spouse. Panting and Merry (1972) reported a divorce rate of 40 per cent whilst Walker, (in Florian and Katz, 1972) found that only 11 per cent of a group of head injured people had divorced.

1.4.4 What keeps couples together?

Zarit, Todd and Zarit (1986) suggest that the length and quality of the relationship prior to the injury is likely to influence the ability to cope with a care-giving role, though not perhaps as much as the amount of affection currently felt for the affected spouse. In a telephone survey of seven couples who had stayed together for between two and seventeen years, Anderson-Parente', DeCesare and Parente' (1990) found couples focused on the positive side of the relationship and viewed their spouses with warmth rather than as a burden. There was a belief that they had been successful in overcoming other

problems in the past and that their marriage had withstood a great deal of hardship. Also, each partner apparently perceived that their mate still cared for them and loved them. The biggest marital problems were in areas of dependency: childlike, self-centred, less considerate. All partners indicated that they felt they were married to a different person since the head injury. Anderson-Parente' *et al.* (1990) estimate that less than a third of couples stayed together two years post injury.

The present study aims to glean some clues about why couples that have stayed together have done so, by exploring what spouses perceive to be the positive aspects of the relationship.

1.5 Why focus on the womens' experiences?

Men are more likely than women to suffer head injuries (Tennant, 1995). This suggests that women may be more likely to find themselves with a head-injured man than vice versa. Much has been written in the literature on carers about the high number of women in caring roles who have responsibility for people with physical problems or disability, but there has been less focus on the womens' perceptions of their relationships. The same is true of women who are in a relationship with someone who has sustained a head injury. Exploring their position is important and has implications for clinical interventions. The focus of the present study is concerned with womens' experiences of their relationship with a head-injured survivor. Having said this, the importance of giving an opportunity to male partners or husbands to express their views is recognised, not only for research purposes but for ethical reasons too. A study which presented solely the views of female partners could be criticised as being unbalanced. Therefore, this study includes the head-

injured husbands in some parts of the data collection.

1.6 Methodology used in the current study

The current study uses two approaches: quantitative and qualitative. These are described fully in the method section. For the quantitative approach, a number of standardised, published and unpublished measures were used.

1.6.1 Qualitative exploration

Whilst some research questions can be addressed by testing hypotheses it is argued here that such an approach alone could impose limitations on the richness of information about the human experience of being in a relationship with someone who has had a head injury.

Henwood and Pidgeon (1995) point out that there are both technological and epistemological reasons for conducting qualitative research, originally described by Bryman (1988). Technological reasons refer to the choice between whether a quantitative or qualitative approach best suits the research in question. For the purpose of the current study, such divisions were not clear cut: it was felt that both approaches would have advantages and offer important findings. The epistemological debate concerns the nature and practice of science and the generation of knowledge. Henwood and Pidgeon (1995) explain that the quantitative paradigm seeks to establish objective truths based on the laws of cause and effect through hypothesis testing. The qualitative paradigm searches for meaning and understanding rather than abstract universal laws.

Sandelowski (1986) argues that 'the truth value of a qualitative investigation generally

resides in the discovery of human phenomena or experiences as they are lived and perceived by other subjects, rather than in the verification of a priori conceptions of those experiences' (p. 30). For her 'a qualitative approach views every human experience as unique, and truth is viewed as relative' (p 29). Hence, it was felt to be important to carry out this form of data collection. Given that this was an intensive study of a relatively small number of participants it was particularly salient to develop this aspect of the research generating critically important data not offered by the quantitative measures. For these reasons, the current study poses a number of open questions to participants with the aim of generating different and equally important information to enrich the quantitative findings. This is also an attempt to keep the participants and their experiences firmly at the forefront of this research.

Unlike a quantitative stance, a qualitative approach openly acknowledges and makes conscious the impossibility for the researcher of remaining distanced and disconnected from the research. The experience of carrying out the research, the impact upon the researcher, the feelings a participant is left with after the interview, and the process of the interviews are all important aspects of research which this study will attempt to acknowledge and learn from.

1.7 Aims and hypotheses

1. To explore changes in couple relationships after TBI as reported by women partners.

Quantitative Hypotheses

1.1 There will be a difference in womens' reports of marital state before and after TBI.

1.2 There will be a difference in womens' reports of aspects of sexual satisfaction before and after TBI.

1.3 There will be a relationship between womens' reports of current marital state and perceived injury-related symptoms experienced by husband.

1.4 There will be a relationship between women perceiving their partners as more dependent since TBI and

a) marital state

b) emotional well-being

1.5 There will be a relationship between womens' reports of marital state and emotional well-being.

Qualitative Exploration

1.6 What aspect of the relationship has changed the most since TBI according to the women partners?

1.7 How do women partners describe the changes in their role/position in the relationship?

2. To explore the impact of personality change after TBI on sexual satisfaction in the couple relationship.

Quantitative Hypotheses

2.1 There will be a relationship between perceived level of mens' sexual interest and womens' ratings of

a) marital state

b) sexual satisfaction

2.2 There will be a relationship between perceived men's coercive sexual behaviour and womens' ratings of

a) marital state

b) sexual satisfaction

2.3 There will be a relationship between womens' perceptions of their partner as a stranger and their ratings of

a) marital state

b) sexual satisfaction

2.4 There will be a relationship between womens' reports of husbands' sexual advances being welcome and womens' avoidance of having sex.

3. To explore each partner's perceptions of the relationship.

Quantitative Hypotheses

3.1 There will be a difference between womens' and mens' reports of aspects of current marital state.

Qualitative Exploration

3.2. What are the women's perceptions of their partners feelings for them?

4. To gain insight into why couples might stay together post TBI.

Qualitative Exploration

4.1 What aspects of the relationship are positive according to the women?

4.2 How do the women see the future?

5. To explore womens' views of services.

Qualitative Exploration

5.1 What help have they received on these issues and what help would they have liked?

5.3 What comments do they have, if any, about services received?

6. To explore how it felt for the women to take part in the research.

Qualitative Exploration

6.1 How did it feel for participants to take part in the research?

6.2 What feelings did it evoke for participants?

CHAPTER TWO

METHOD

2.1 Design

The design is a within-group correlational and repeated measures design. The hypotheses in this study are concerned with women's perceived differences in marital states and sexual satisfaction before and after their husbands or partners had sustained a head-injury. Differences in current perceptions of aspects of marital state between husbands and wives were also investigated. These comparisons and the correlations between marital state, sexual satisfaction, emotional state and problems relating to impairments following head injury meant it was necessary to examine factors within the experimental group, rather than compare them with another group.

2.2 Participants

2.2.1 Inclusion and exclusion criteria

In order to keep the sample as homogenous as possible the inclusion criteria were stringent:

1. Couples where the male partner had sustained a traumatic head injury between one and seven years ago. The reason for this time interval was that by one year following the injury, the process of physical and cognitive recovery in the head-injured person would have slowed. Also, spouses would be at a stage of having to adjust to the changes: the time course of relatives' distress has been shown to be the same at six months and one year after the accident (Oddy *et al.*, 1978). Brooks, Campsie, Symington, Beattie and McKinlay (1986) found that relatives' stress did not reduce in five years post injury. An upper time limit of seven years after the injury was adopted to focus the study on the couples' adjustment during the early years after the injury.

2. The couple were in a stable relationship prior to the injury;

3. The couple were still together since the injury;

4. Post-traumatic amnesia lasted at least 7 days.

The excluding criterion was previous psychiatric history in the male which could have been a confounding variable on the state of the marital relationship prior to the head injury.

2.2.2 Recruitment

Participants were recruited through two sources: a head injury rehabilitation service and Headway charity, a national association for head-injured people and their families. A number of couples who did not fit the inclusion criteria were excluded: thirteen couples were excluded where the female partner had sustained the injury and fifteen couples were excluded because they had already separated. Out of a total of 42 couples contacted, 18 took part, representing a response rate of 43 per cent.

Recruitment through a head injury rehabilitation service

Couples who fitted the inclusion criteria were identified by senior clinicians working in the specialty. Personalised covering letters (appendix 1) accompanying the author's first contact letter and a refusal only reply slip (appendix 2), information sheet (appendix 3), consent form (for information only) (appendix 4) and Freepost envelope were sent to them. A decision was made to write separately to each partner of the couple, reflecting the confidentiality that would be maintained should the couple decide to take part. A total of 40 letters were sent to each partner of 20 couples. In response to requirements from an ethics committee, a second letter checking for active consent to a telephone call was sent to those potential participants who had not actively

declined taking part (see section headed Ethics). Given the network and nature of contacts of the author's supervisor, as well as high response rates in previous research projects within this service, a high response rate was expected in this study. Nine couples, representing a 45 per cent response rate, consented to telephone contact (guided by the brief in appendix 5), all of whom agreed to take part in the study. Appointments were made to visit the couples in their own homes.

Other factors with recruitment from this source

One spouse had telephoned the contact number which had been provided saying she would like to participate but she was now divorced. This woman was thanked for her trouble but was not included in the study because of the confounding variable of divorce. She was offered a copy of a summary of the findings which she accepted.

One gay couple were known to fit the inclusion criteria. Whether or not to include them in the study required careful consideration: it could be argued that to exclude this couple was discriminatory. However, it was felt that to force them into using measures that were designed for heterosexual couples would have been disrespectful and dismissive of the differences that exist between heterosexual and homosexual relationships (Kitzinger and Coyle, 1995). Furthermore, any changes in relationship state and emotional state could be explained by other factors not common to heterosexual couples such as homophobia, bigotry, and discrimination in service delivery and institutions.

Recruitment through Headway charity

The co-ordinators of six branches of Headway in the south-east were contacted. Meetings were

arranged in which the nature and purpose of the study was explained. Where meetings could not take place the same information was conveyed by telephone and followed with written details. Branch co-ordinators informed the author how many couples they were aware of who fitted the inclusion criteria. The author then supplied the co-ordinator with "packs" containing first contact letter (appendix 6) and opt in reply slip, information sheet, consent form (for information only) and Freepost envelope. Blank envelopes and postage was provided. A total of 22 couples were contacted through this source; as with those letters sent through the head injury rehabilitation services, each partner was written to separately. Nine couples, representing a 41 per cent response rate, consented to telephone contact (guided by the brief in appendix 5), all of whom agreed to take part in the study. Appointments were made visit to the couples in their own homes.

Other factors with recruitment from this source

The author's concern regarding recruiting an adequate number of participants led to exploration of placing an advert in Headway's national newsletter to target a slightly broader range of couples in the south-east. Unfortunately, this is only produced quarterly and it was not possible to place an advertisement in enough time for first contact letters to be sent and interviews arranged and carried out.

One couple returned reply slips giving permission for the author to telephone them, however when they were contacted the author was informed by the female partner that her husband had died only the day previously. Clearly, this was not foreseen and apologies were offered for the untimely nature of the call; the level and nature of support available to her was established and the author felt satisfied that she was supported with family members and friends. Apologies were accepted.

One man telephoned the contact number and spoke to the secretary of the rehabilitation services informing her that he did not wish to take part, especially as he did not want there to be any possibility of his wife getting upset. He confided that since the injury things had been extremely distressing for both he and his wife; life had been an enormous strain for them. He said that they would continue coping without help and when the secretary suggested that the author contacted him (with a view to giving information about helping services, if required, and to acknowledge the impact of receiving the first contact letter, as well as the impact of the injury), he declined further contact. The author ensured that the impact of this call on the secretary was addressed and spent time discussing this with her.

2.2.3 Description of sample

Eighteen heterosexual couples in which the male partner had sustained a head injury took part in the study. Because a component of this study has used a qualitative approach a selection of case histories, selected because their situations represent a broad range of circumstances, are described in appendix 7.

2.2.4 Demographic information

The mean age of men was 42.06 (SD = 12.49) and of women was 39.17 (SD = 11.14). The average time that participants had been in their relationships was 16.17 years (SD = 9.42 years), with a range of 5 to 40 years. Eleven of the couples had children living at home: two couples had one child; six couples had two children; and three couples had three children.

Mens' occupations and mental health before the injury

All the men were employed prior to their injuries. They had various occupations prior to their

injury: building trader, pilot, salesperson, bank manager, cab driver, dispatch rider, fire-fighter. None of the men had psychiatric problems prior to their accidents although two reported experiencing job-related stress. Neither of these appeared to constitute a psychiatric problem, hence they were included in the study.

History of the accident

The mean number of years since the husbands' head injury was 4.14 (SD = 1.94) with a range of one to seven years.

Seven of them were driving cars at the time of the accident; two were car passengers; three were pedestrians; three were cyclists; two were pillion passengers; and one had a work tool fall on his head from a height.

The average length of time that men were unconscious was just under two-and-a-half weeks (*M* = 2.36, SD = 2.86), with a range of one to seven weeks.

Nine couples were waiting for compensation claims to be settled.

Mens' occupations and mental health after the injury

All the men were unemployed since the injury. Two men reported a noticeable increase in stress since their injuries; one had since received treatment for "obsessive behaviour" and another for "obsessive thoughts". All the men were physically mobile and able to carry out self-care.

Women's occupations after the injury

All but two of the women had continued with the same employment as they had prior to their partner/husband's injury. The two that had not continued in employment had become full time students in order to increase their future employment potential.

2.3 Quantitative Measures

These are presented in the order that they were given to participants.

2.3.1 Demographic and neurological information (appendix 8)

This was gathered in the form of a structured interview with the couple. It covered personal details about each partner: age, emotional and physical problems prior to the injury, length of time the couple had been together, length of time since the accident; details of the injury; compensation; and comments on services received.

The following measures were given to the women only:

2.3.2 General Health Questionnaire 12 (Goldberg, 1992) (appendix 9)

This is a 12 item questionnaire with Likert scale responses. It is a shortened version of the GHQ 28 (Goldberg, 1978) and was designed to detect non-psychotic psychiatric disorder in people in the community. It was constructed to identify cases, but is also used to measure a degree of disorder. Also, it is a frequently used measure in research of relatives' distress and so it enables comparison studies to take place more easily. Therefore, it was felt to be an appropriate measure of emotional well-being for the purpose of this study.

Split-half and test-retest reliability is .83 and .73 respectively. Validity has been evaluated by

assessing its sensitivity in detecting cases of psychiatric disorder and has been found to be satisfactory (Goldberg, 1978).

There are two methods of scoring this questionnaire: GHQ scoring, where responses score 0, 0, 1, and 1, respectively; and Likert scoring, where responses score 0, 1, 2, and 3 respectively. The first method gives scores ranging form 0 to 12 and is suitable for detecting cases; the second method is useful for comparing degree of disorder, ranging from 0 to 36. Both methods of scoring have been used in data collection for this study.

2.3.3 Injury-related symptom checklist (appendix 10)

This is a 75 item checklist designed and used by clinicians in head injury services. Most items are concerned with frequency of behaviour, memory and reasoning problems. The spouse was required to choose one of four options ranging from "almost never" to "almost always" to indicate how often they felt each item occurred for the head injured person in the previous six months.

The checklist was based on the Katz Adjustment Scale (Katz and Lyerly, 1963) a scale for measuring the adjustment and social behaviour of people with mental health problems in the community. It has adapted for use for people with head injuries (Oddy, Humphrey and Uttley, 1978; Oddy, Coughlan, Tyerman and Jenkins, 1985).

The scores used in the present study are the total scores calculated for each participant, scores were derived from ratings "almost never" as 1, through to "almost always" as 4 and all the items were totalled. Spearman's correlation coefficients were calculated to assess split-half reliability, these were found to be .61, accounting for 36 per cent of the variance.

2.3.4 The Golombok and Rust Inventory of Marital State (GRIMS, Rust, Benmun, Crowe and Golombok, 1988) (appendix 11)

This is a 28 item questionnaire used for the assessment of the overall quality of a couples' relationship, with a four point Likert scoring scale with responses ranging from "strongly disagree" to "strongly agree". It was developed for use with heterosexual couples. The scale which can be used for either men or women and has good reliability (.90 for women and .92 for men); content and face validity are high.

Female participants were asked to complete this questionnaire twice, once retrospectively in relation to how they subjectively remembered their relationship prior to their partner's injury. For the second time of completing the questionnaire, participants were asked to respond to the items relating to how they found their relationship at the time of interview. Scores were obtained by totalling the numbers which correspond to the responses given.

2.3.5 Selected items from the Golombok and Rust Inventory of Sexual Satisfaction (GRISS, Rust and Golombok, 1986)

The GRISS is a 28 item measure for exploring the quality of a sexual relationship and of a person's functioning within it (appendix 12). It was developed using data collected from heterosexual couples in sexual relationships and provides measures for each gender separately. Split-half reliability is high (.94 for women and .87 for men); validity is also good. Scores are available in the following subscales: communication; dissatisfaction; genital physical contact, avoidance of sex, and frequency of sexual activity. Respondents are asked to choose one of five answers on a five point Likert scale.

In the present study only eight items were selected for use (appendix 13). These comprised two subscales, non-communication and avoidance, and half of a third subscale, sexual dissatisfaction, where two items from the four-item subscale were used. The remaining items were considered to be too intrusive to explore with people who were not known to be actively attending couple/marital therapy and also too intrusive for the purpose of this study.

As with the GRIMS, participants were asked to complete this questionnaire twice, once retrospectively in relation to how they subjectively remembered their relationship prior to their partner's injury. For the second time of completing the questionnaire participants were asked to respond to the items relating to how they found their relationship at the time of interview.

Scoring was carried out by totalling the corresponding numbers to the responses given as with the full GRISS.

Test-retest reliability was assessed by giving the questionnaire to the same participants twice, with a two week interval. For the before injury questionnaire, there was 73 per cent concordance between the two administrations, and 98 per cent concordance +/- 1; for the since injury questionnaire, there was 79 per cent concordance between the two administration, and 96 per cent concordance +/- 1.

2.3.6 Relationship Change Questions (appendix 14)

This was initially a five item questionnaire designed by the author which was based on information gathered from meetings with senior clinicians in the specialty, based on findings from their clinical experience. Responses to items were on a Likert scale:

"my partner has felt like a stranger to me since the injury"

yes, definitely; yes, sometimes; no, not much; no, not at all.

This was amended during the first interview when the participant identified another relevant item (no. 6 on the questionnaire) which she felt it would be important to include; this was subsequently added giving the scale a total of six items. The added item, "my partner is just as interested in our sexual relationship now as he was before the injury", was indeed found to be relevant by other participants. Scores from single items were used for the analyses. The questions were felt to have good face validity and most participants reported that they felt the items were very relevant.

Test-retest reliability was assessed by giving the questionnaire to the same participants twice, with a two week interval. There was 79 per cent concordance between the two administrations, and 100 per cent concordance +/- 1.

2.3.7 Items from GRIMS given to the head-injured men (appendix 15)

In view of problems of fatigue, memory and information-processing, as well as variations in the severity of these problems, it was felt important to keep this measure brief. Eight items only were selected from the GRIMS. Examples were:

"We both seem to like the same things"

"I never have second thoughts about my relationship".

Scores were obtained by totalling the numbers corresponding to the answers given.

Test-retest reliability was assessed by giving the questionnaire to the same participants twice, with a two week internal. There was 75 per cent concordance between the two administrations, and 98 per cent concordance +/- 1.

2.4 Qualitative questions

2.4.1 Open questions to female spouses (appendix 16)

In order to enrich the information gained from the questionnaires and gain greater understanding of the human experience of living in an intimate relationship with a head-injured man, participants were asked a number of open questions. The aim of incorporating a qualitative approach in tandem with a quantitative one was not to 'triangulate' the two sets of data (checking different findings against each other), but to allow the quantitative component to reveal a general framework and the qualitative phase to explore details of how and why such a general framework was found. This is described by Bryman and Burgess (1994).

The open questions were based on information generated from meetings with senior clinicians in the specialty. For example, wife's perceptions of changes in her role, perceptions of her partner's feelings for her, how she sees the future, and positive aspects of the relationship.

2.4.2 Open questions to head-injured males

For the head-injured men, after they had completed the 8 item questionnaire, they were asked if there was anything they felt it was important to say regarding how they felt their injury had impacted upon their relationship. The problem with this question was that because of its abstract

nature it might have been difficult for them to understand. Nevertheless, it was felt important to attempt to gain an understanding of the men's experiences and so this question was asked. Because of limitations imposed on the current study, this information is not reported here.

2.4.3.Evaluation of qualitative findings

Three concepts were used to guide the evaluation of this component: auditability with regard to objectivity, respondent validity (Henwood and Pidgeon, 1995), and inter-rater reliability (Silverman, 1993).

i) Auditability refers to being explicit about the how the findings are derived, allowing others to follow the same steps. The quotes from interviews, grouped under categories, are offered in appendix 26 for scrutiny and auditability. Objectivity acknowledges the researcher's bias in the process.

ii) Respondent validity means that participants should recognise and agree with the researcher's interpretations. This will be explored by inviting feedback from participants when they have received a summary report (currently being prepared). Validity was also explored by examining the transcripts of the interviews for evidence that refuted the concepts. The information gained in the debriefing questions indicate the value of the study.

iii) Carrying out inter-rater reliability in qualititative research is a debatable issue: Sandelowski (1986) argues that to do so contradicts its ethos because a different set of assumptions is being used. In her view, the concern for the reliability of observations arises only within the quantitative research tradition. She argues that qualitative research, where the uniqueness and diversity of

human experience are sought, does not therefore lend itself to reliability testing. However, Silverman (1993) cites Kirk and Miller (1986) who argue that "qualitative researchers can no longer afford to beg the issue of reliability" (p.72). On the basis of attempting to incorporate systematic rigour in the present study, a decision was made to explore the extent to which the same results were yielded: an independent rater followed the same steps as above. Strong agreement, 100 per cent concordance, was found in the broad themes and close agreement found in the categories that were identified by both author and independent rater (appendix 27).

2.5 Procedure

2.5.1 Interviews

The presence of the author was felt to be important whilst participants completed the questionnaires. If participants did not understand words or the questions, then the author would be available to answer any questions and offer greater clarity, thereby increasing the likelihood of more reliable responses. Also, if distress was manifested as a result of completing the questionnaires, the author was available to respond to it. Therefore, visits in person were felt to be the most appropriate method for gathering information.

In order to reduce inconvenience to participants, interviews were carried out in the couples' homes. Initially, both partners were seen together and the procedure was explained. During this time together they signed consent forms and verbally answered questions about demographic and neurological details. This process was conducive to building rapport and trust. Following this, each partner was seen separately; where possible, the female partner was seen first. Questionnaires were given to the women for completion, then the open questions, with prompts where it was felt appropriate, were asked; a decision was made to record participants' responses

verbatim rather than tape record the interviews, which the author felt to be intrusive. On average, information gathering and interviews with the women took between one-and-a-half and two hours each; information gathering from the head-injured men took approximately 20 minutes. The reason for spending more time with the women was related to them being the focus of the study. However, it was felt to be important to include the men as much as possible, not only out of courtesy but to give them an opportunity to express their views, and also to allow comparisons of their responses with the same questions that their spouses were asked. It was felt that this could offer insights into the different perspectives of both partners.

2.5.2 Debriefing

Five "End of Visit Questions" (appendix 17) were verbally asked to the men and women (in confidence) after they had each completed the above questionnaires. These explored: what it felt like to take part in the study; what feelings were evoked; whether there were any questions they did not answer; and whether, in their opinion, anything should or could have been done differently. Only the women's responses are reported here. Participants were also asked whether they would like a standard letter sent to their GPs informing them that they had taken part in the study.

Participants were also given details of local services should they have felt the need to ask for help either because of difficulty in coping with the emotional consequences of the head-injury, or because taking part in the interview might bring to the surface existing distress to which participants may want to respond to (appendix 18). With the latter of these in mind, the author offered a follow up telephone call to each participant.

A "Request for a Summary of Findings" sheet (appendix 19) was given to each person should they wish to have this information when findings had been collated.

2.6 Ethical considerations

Given the sensitive and intimate nature of the study consideration was given to the experience of participants being faced with questions which they may perceive as intrusive or uncomfortable. It was anticipated that an existing ethics committee at the rehabilitation hospital would be able to scrutinise an application for ethical approval. However, it was discovered at a later date that this committee did not in fact exist. Then, the opinion of a senior professional in the field was sought, whose response was that the proposal was felt to be 'very reasonable' (appendix 20). This letter contained a disclaimer of ethical responsibility and so other committees had to be approached. An independent ethics committee gave approval for those participants the author intended to recruit via Headway charity (appendix 21).

A proposal was submitted to the Local Research Ethics Committee (LREC) for accessing potential participants through a head injury service. The author was verbally informed that the committee had given approval on the condition of one amendment: that a contact number was added to the personal letters to be sent to the potential participants. Accordingly the letters were amended. The reply slip enclosed was a refusal only one, allowing the author to make telephone contact if it was not returned. It was anticipated that because of the likelihood of potential participants leading busy lives with multiple commitments, this would inconvenience them less. Some weeks later, the author received a letter from the LREC (appendix 22) confirming the amendment, but another was required. This was that potential participants were given the option to give active "opt in" consent to the telephone call rather than refusal only. In view of the fact

that a number of first contact letters had been sent out the author proposed that a second letter be sent, with an active consent slip giving permission to make telephone contact, to those people who had not already actively declined any contact (appendix 23). This was accepted by the LREC and full ethical approval was subsequently given (appendix 24) with a requirement that the clinical director agreed to the research taking place within the service setting (appendix 25).

2.7 Analysis

2.7.1 Quantitative Analysis

The nature of the data set obtained is ordinal. Although parametric analysis dictates the parameters of interval scaling, as well as a normal distribution of responses within the research sample, and homogeneity of variance, it was felt appropriate to apply the more powerful parametric analysis where possible. This was because the latter two conditions were fulfilled and research processes often accept that 2 out of 3 parameters may be met without seriously affecting the power and robustness of the test (Bryman and Cramer, 1990).

Two kinds of analyses were carried out on the data set.

1. Comparative:

comparing women's reports of current marital state with their reports of their marital state before their partner's injury;

comparing women's reports of aspects of their current sexual relationship with their reports of their sexual relationship before their partner's injury;

comparing men's responses to women's responses on those items of the GRIMS which both partners answered.

2. Correlational, exploring relationships between women's reports of:

emotional state and marital state;

marital state and level of injury-related problems they believed their partners to have;

reports of husbands' personality changes and marital state;

reports of husbands' personality changes and aspects of sexual satisfaction.

The computer package SPSS for Windows was employed to carry out these analyses (SPSS Inc., 1993).

2.7.2 Qualitative Analysis

Aspects of grounded theory were used as a guide to explore the data from the open questions (Henwood and Pidgeon, 1995). A decision was made to limit the qualitative analysis to the development of abstract concepts only. Henwood and Pidgeon (1995) suggest that a variety of research activities can take place which do not require the building of a 'total theory.' The areas of investigation were introduced in the wording of the open questions; from the responses to these, a number of categories were evolved. This was the key process that served to organise the

information from the transcripts. The steps taken were as follows:

i) All the interview material was transcribed onto a word processor. It was then read and re-read.

ii) All responses observed were cut and then pasted, using a word processor, with other responses that the author considered to fit under a shared category. Eventually, all quotations had been pulled out, listed and sorted into categories of data (appendix 26).

iii) The categories were examined for shared themes.

iv) The next step was to devise concepts that the author felt best described the themes that emerged.

CHAPTER THREE

RESULTS

3.1 Preliminary analyses of demographic variables

In order to find out the influences of demographic variables on the dependent variables, in other words the associations between demographic and dependent variables, a set of preliminary analyses were carried out using Pearsons correlations. These indicate a number of significant findings. The total number of correlations performed to carry this out was 77. With such a high number of correlations, five per cent would have been expected to have occurred by chance alone. Therefore, to take this into consideration the significance level acceptable is adjusted to $p < .01$ which produces two significant findings: increased age of women is related to greater likelihood of viewing the husband as a stranger after his head injury ($r = .59, p < .01$); and the longer the time a couple have been together, is related to lowered sexual satisfaction before the husband's injury ($r = .67, p < .01$).

3.2 Analyses of hypotheses and qualitative explorations

3.2.1 Changes in couple relationships since injury as reported by female partners

Quantitative results

Hypothesis 1.1: There will be a difference in womens' reports of marital state before and after TBI.

A highly significant difference was found in female reports of marital state before and after husband's injury, in the direction of the marriage worsening, which supports the hypothesis ($t = 7.05$, df 17, $p < 0.001$, two-tailed). The raw data indicated one exception to this where the scores before and after remained within the 'very severe problems' range.

Scores of reports of marital state before injury had a range of 13 to 51 ($M = 24.72$, SD = 9.25). According to normative data this mean score represents a 'good marriage' (appendix 11). Scores of reports of marital state after injury had a range of 29 to 54 ($M = 42.72$, SD = 7.49). According to normative data this mean score represents 'marriages with severe problems'. Sixteen out of eighteen of the women rated their marriages as 'poor', 'bad', 'with severe problems' or 'very severe problems' since the injury.

Hypothesis 1.2: There will be a difference in womens' reports of aspects of sexual satisfaction before and after TBI.

A highly significant difference was found in female reports of aspects of sexual satisfaction before and after their husband's injury, in the direction of lower satisfaction after the injury, supporting the hypothesis ($t = 4.01$, df 15, $p = 0.001$, two-tailed).

Scores of reports of aspects of sexual satisfaction before injury had a range of 1 to 26, where the maximum possible score was 32 and minimum possible score was 0 ($M = 8.88$, SD = 5.83). Scores of reports of aspects of sexual satisfaction after injury had a range of 4 to 32 ($M = 15.13$, SD = 7.41).

Two women did not complete the post-injury questionnaire as in both cases they reported a complete cessation of their sexual relationship. Twelve others rated their sexual relationship as worse since the injury and three rated it as being the same and only one as improved.

Hypothesis 1.3: There will be a relationship between womens' reports of current marital state and perceived injury-related symptoms experienced by husband.

A Pearsons r was calculated and was found not to be statistically significant ($r = 0.49$, $p = .85$, two-tailed), therefore, not supporting the hypothesis that there is a relationship between spouses ratings of injury-related symptoms and marital state.

Hypothesis 1.4 a): There will be a relationship between women perceiving their partners as more dependent since injury and marital state.

A rating of dependency was scored by spouses. However, seventeen out of eighteen participants reported their husbands as being 'definitely more dependent' since the injury; the eighteenth reported her husband to be 'sometimes more dependent'. This produced a ceiling effect which does not allow this hypothesis to be statistically tested.

b): There will be a relationship between women perceiving their partners as more dependent since injury and emotional well-being.

As stated above the unanimity of spouse ratings once again created a ceiling effect which does not allow this hypothesis to be statistically tested. Responses to another question asking women to rate the extent to which they felt their role had changed since the injury confirmed

how important this was: all 18 women answered 'yes, definitely' to the statement 'my role within our relationship has changed a lot since the injury'.

Hypothesis 1.5: There will be a relationship between womens' reports of marital state and emotional well-being.

Emotional well-being as measured by the GHQ was scored in two ways. Scoring by the Likert method identified the level of distress. A Pearsons correlation was found not to be statistically significant, therefore, not supporting the hypothesis ($r = .29, p = .25$, two-tailed).

The GHQ scoring method allowed clinical 'caseness' to be identified. Eleven out of the eighteen women had scores at and/or above the level of clinical caseness, indicating that 61 per cent of the women in the study had a level of emotional distress that is cause for concern.

Qualitative questions

1.6: What aspect of your relationship has changed the most since your husband's injury?

Categories generated from answers to this question and their frequencies are shown in Table 1. As with all the qualitative tables of results in this section, the frequency of times each category was mentioned does not represent its level of importance. For example, although only four women out of the eighteen women talked about their husbands' aggressive tempers it was such a big feature in the couple's lives that for them it was the biggest change.

Strain from putting up with things	9
Isolation as a couple	7
It's made me stronger as a person	7
Husbands' lack of insight	7
Husband's total dependency	6
I've lost and equal partner	6
I've lost a close companion	6
Feel stigmatised; people don't make allowances	6
Aggressive temper	5
I'm always on guard with his unpredictable temper	5
Emotional side 'badly damaged'	5
Sexual relationship.	12

Table 1: Categories generated from answers to the question 'What aspect of your relationship has changed the most since your husband's injury?'and frequency with which they were reported.

Characteristic of all the responses to this question was the theme of loss of the core person.

> "I was really struck when two weeks after the accident, P had come home and my 7 year old asked when's my Daddy coming home? That said it all for me. It's like being married to a completely different person; if I'd met P after the accident I wouldn't have married him.'

For all but one spouse the losses were seen as negative and sad. The one spouse who reported many of the changes as positive said that the marriage was 'on the brink of divorce at the time of the accident' and she had wanted more control in the relationship anyway.

Five broad themes emerged from the categories in terms of how salient they were to participants. Evidence to support these findings will now be presented.

i) Loss of a partner and companion.

Robyn particularly missed the joyful side of their relationship:

> "we're no longer an equal partnership - I feel like I've lost my best friend."

ii) Husbands' mood swings.

In Pam's words:

> "It's like treading on eggshells all the time now, he's so explosive and I end up bottling everything up. I've found that a terrible strain. He's unpredictable; everything can seem fine but then within 10 minutes he goes ballistic. I know a lot of it is about anger that the accident happened but the outbursts are often so unreasonable. It's also because of Tom being really stubborn, he's rigid in the way he sees things now and his views are more extreme and opinions are stronger."

Others spoke of physical abuse.

iii) Strain and distress of the wives.

Three women had what they described as a 'complete breakdown' within the first year after their husbands' injury.

> "The first eight to twelve months were especially difficult because of Daniel thinking he could do things which he couldn't, like riding his bike, and that's always been a source of conflict and disagreement."

Some talked of frequent frustration and "bottling up their feelings" to "stay strong." Pam was concerned about how stressed she was with "sky high" blood pressure feeling uptight most of the time. For Emma, her fears were related to feeling oppressed in the sexual relationship:

"It feels important to say how it feels to be living with the fear I feel. The pressure I feel under in relation to our sexual relationship feels in many ways more oppressive than if I were being constantly physically abused."

iv) Isolation and feeling stigmatised.

The invisible nature of the disability was felt by many women to have resulted in them being cut off from the outside world; some felt stigmatised, especially with their husband being unemployed. Sometimes the isolation was related to the temper of the head injured person driving others away.

"People don't understand or make allowances, because you can't see what's wrong."

v) Changes in emotional and sexual relationships.

"I was totally unprepared for the changes in our relationship, I knew he'd have memory difficulties and speech problems, but I thought we'd still be a couple. The emotional side feels badly damaged, I really miss the intimacy and closeness. Suddenly we had none, There are times when I'd love to be swept off my feet and loved just for me especially when I've tucked the last child into bed at night. I don't want to get to 70 and not have felt that warmth and closeness again. I can see frustrations setting in."

Three women gave a specific explanation for the lack of sexual interaction with their husbands:

"because he's so dependent on me and I'm much more like a mother to him, it doesn't feel right that we have sex. I know I'm not the only one that feels like that because in the carers support group, about three other women said they felt the same."

Emma was contending with changes in the opposite direction from most of the women in the study, with Daniel being much more persistent sexually:

> "He gets so full of aggression and is so persistent: this went on for ages with him being verbally persistent and wanting to have sex with me and one night I just got really frightened and ran out of the house to a neighbour who I stayed with."

1.7: How would you describe the changes, if any, in your role in your relationship?

Categories generated from answers to this question and the frequencies of them being reported are shown below in Table 2.

Total responsibility	14
Role reversal	8
Lost a husband, gained a child	7
Unable to trust him	6
being the breadwinner	5
"down to me to motivate him"	4
"decision making is all my responsibility"	5

Table 2: Categories generated from answers to the question 'How would you describe the changes, if any, in your role in your relationship?'

The biggest theme which emerged from these categories was more responsibility, exemplified by parenting roles and decision making.

i) Greater parental role towards husband.

All the women in the study had become 'the breadwinner' since the injury. Five described this as being more like mothers than partners to their husbands. This often involved pre-empting, for safety reasons, what they thought their husbands might do when left alone.

> "I've been like a mum and a dad to him, our roles completely reversed. I had to take responsibilities, become stronger, and grow up suddenly. ..... it's like having another child; he's very vulnerable and sensitive. It means we no longer have a sharing relationship, he's doing all the taking."

ii) Decision making.

Like most of the couples in the study, Robyn says that Charlie used to take charge of everything especially finances so she had to learn to deal with that. It was commonly reported that the taking on of responsibilities had made them grow up, or become stronger.

> "All the decisions are mine, especially when it comes to money - V is hopeless with that. I carry all the responsibilities while V just drifts through life with it all being rosy for him. One of the questions on the questionnaire was about being competitive when making decisions, ... that's never the case for us because I make them all anyway."

<u>Developing a concept from the above two questions</u>

In terms of more abstract concepts all these changes can be described in terms of losses and extra demands. The losses tend to be related to aspects of the relationship previously seen as positive: loss of an equal partner and companion;

intimacy; closeness; and emotional support. These components of relationships are much reduced in the sample group. The demands can be seen as aspects of greater responsibility, such as decision making and becoming the breadwinner. Yet for some women, particularly those who had described themselves as passive before their husbands injury, these greater demands were seen to contribute to a process of forcing them to grow up.

3.2.2 The impact of personality change post-TBI on sexual satisfaction in the couple relationship

Quantitative results

Hypothesis 2.1: a): There will be a difference between perceived high levels of mens' sexual interest and perceived low levels of male sexual interest with regard to womens' ratings of current marital state.

Spouse reports of both more and the same level of sexual interest since injury were compared with reports of less sexual interest with regard to total scores on marital state (Mann-Whitney U = 31, p = .69, two-tailed). The hypothesis was rejected. Seven women said that their husband's level of sexual interest since the injury had decreased, seven said it had stayed the same and three said it had increased.

b): There will be a difference between perceived high levels of mens' sexual interest and perceived low levels of male sexual interest with regard to womens' ratings of sexual satisfaction.

Spouse reports of both more and the same level of sexual interest since injury were compared with reports of less sexual interest with regard to total scores on aspects of sexual satisfaction. The hypothesis was rejected (Mann-Whitney U = 26.5, $p = .70$, two-tailed).

Hypothesis 2.2: a): There will be a relationship between perceived coercive sexual behaviour and womens' ratings of marital distress.

Spearmans rho was not found to be significant indicating that where women perceive their husbands as sexually coercive this is not associated with increased marital distress ($r = .28$, $p = .33$, two-tailed). The hypothesis was rejected.

Sixty per cent of the sample group have felt sexually coerced to varying degrees by their husbands since the injury. To the statement 'My partner's sexual advances sometimes feel coercive to me' there were fifteen women gave responses and three did not. Three women responded 'yes, definitely'; six said 'yes sometimes' (the modal response); four said 'no, not much'; and one said 'no, not at all.'

b): There will be a relationship between perceived coercive sexual behaviour and womens' ratings of sexual satisfaction.

Spearmans rho was found to be significant indicating that higher perception of husbands' coercive sexual behaviour were associated with lower levels of spouse sexual satisfaction ($r = .65$, $p < .05$, two-tailed). This result supports the hypothesis.

Hypothesis 2.3: a): There will be a relationship between womens' perceptions of their partner as a stranger and spouse ratings of marital distress.

Spearmans rho was not found to be significant indicating that there is not a relationship between spouse perceptions of their husband as a stranger and ratings of marital distress ($r = .25$, $p = .32$, two-tailed). The hypothesis was rejected.

To the statement 'My partner has felt like a stranger to me since the injury' all eighteen women responded. Eight women responded 'yes, sometimes' (the modal response); six women said 'no, not much'; two said 'yes, definitely' and two said 'no, not at all.'

b): There will be a relationship between womens' perceptions of their partner as a stranger and spouse ratings of aspects of sexual satisfaction.

Spearmans rho was not found to be significant indicating that there is not a relationship between spouse perceptions of their husband as a stranger and ratings of aspects of sexual satisfaction ($r = .04, p = .89$, two-tailed). The hypothesis was rejected.

Hypothesis 2.4: There will be a relationship between womens' reports of husbands sexual advances being welcome and womens' avoidance of having sex.

Spearmans rho was calculated and found to be highly significant indicating that the less welcome husbands' sexual advances were, the more the women avoided having sex with them ($r = .86, p < 001$, two-tailed), supporting the hypothesis.

To the statement 'My partner's sexual advances are welcomed by me most of the time' fourteen women responded. Seven responded 'yes, sometimes' (the modal response); three women said 'no, not much'; two said 'yes, definitely' and two said 'no, not at all.'

3.2.2 Partner's perceptions of the relationship

Quantitative results

Hypothesis 3.1: There will be a difference between female spouses' and husbands' reports of aspects of current marital state.

A highly significant difference was found with wives reporting more marital distress than husbands on the same items, supporting the hypothesis (t = -4.96, df 15, p< .001, two-tailed).

Scores of husbands reports of aspects of marital state (eight items from the GRIMS) had a range from 2 to 13, with a minimum possible score of 0 and maximum of 24 (M = 7.69, SD = 3.24). The same items scored by spouses had a range of 6 to 16 (M = 11.94, SD = 3.44).

Qualitative questions

3.2: What do you think are your partner's feelings for you?

The categories generated by answers to this question are shown in Table 3 below.

Full of gratitude	7
Openly affectionate	6
I don't know what his feelings are	5
Never shows me any affection	4
I think he loves me	4
He thinks nothing has changed	2
He blames me for all the misery in his life	1
He's always anxious to make me happy	1

Table 3: Categories generated from answers given to the question 'What do you think are your partner's feelings for you?'

Three broad themes emerged from these categories.

i) Uncertainty about their husbands' feelings for them.

Some womens' uncertainty appeared to be related to a continuation of lack of communication of feelings before the accident. Pam's uncertainty was tainted with despair:

> "He's always found it difficult to say what he feels. I'm not sure whether he'd be bothered if I wasn't here."

ii) Certainty about husbands' feelings of gratitude.

As with other couples, Sophie responds to Alistair's gratitude with ambivalence:

> "I know he's very grateful to me ... he puts little notes in cards to me at Christmas saying how he couldn't have got by without me. I wish he wouldn't do this because it reminds me that he's dependent on me and I'm not entirely comfortable with that."

iii) Certainty about husbands' feelings of affection towards them.

Emma feels that Daniel loves her a lot, but dislikes his sexual expression of this which does not feel loving to her at all. Linda says John openly expresses affection, although this too is not straightforward:

> "He's generous and constantly worried about doing the right thing to keep me happy, which can feel a bit suffocating; he sometimes gets it wrong. I think his self-esteem is so low that if he's doing something for me that makes him feel a bit better,"

Developing a concept from this question

It was salient that some of the women were attempting to put together pieces of a puzzle to make sense of their confusion about their husbands' feelings for them. This left them guessing and trying to arrive at explanations about how their husbands felt. Other women were in no doubt about their husbands' feelings, although even when these were feelings of affection; for some of the women this was not mutual. Given what was found previously, that there is a perceived "loss of the core person" the women were with before the accident, coupled with the gained responsibility over that person's life, it is not surprising to find such ambivalence and confusion.

3.2.4 Insights as to why couples might stay together after TBI

Qualitative Exploration

4.1: What aspects of your relationship do you view as positive?

Responses to this question are shown below in Table 4.

Companionship	7
A sense of commitment	6
Good communication	2
Reliable	1

Table 4: Categories and frequency with which they were described generated from answers to the question "What aspects of your relationship do you view as positive?"

Three broad themes emerged from these categories.

i) Commitment.

Although Linda expressed doubts about the relationship, she feels that John is very committed; she hopes they can 'sort things out':

> "He's very anxious that our relationship works. His parents divorced and he says he doesn't want to go through that."

ii) Companionship.

Like Sophie, Emma felt that Daniel's role in helping with the children was positive. Robyn also had help at home form Charlie. Sophie describes Alistair as dependable and trustworthy; she values his tolerance and the fact that he has never said anything nasty to her; she is also relieved that Alistair still has his sense of humour:

> "Some people say that victims of head injury would be better off dead, but I've never wished that. It's true that things aren't the way they were before, but Alistair is still Alistair and that's saved us."

Linda felt that she was beginning to see John more as an equal partner. In fact, last year when she had treatment for panic attacks, she was deeply touched when John was more supportive than she expected him to be.

iii) Ambivalence about whether or not positive aspects exist within the relationship.

Six women were silent then after a few moments said "that's very difficult to say." One said 'apart fromcommitmentt, nothing.' 'One said 'none.' Pam felt there was nothing left for her in the relationship but, despite financial independence, she was unable to consider her options:

> "I think of leaving but I feel guilty for even thinking that."

4.2: How do you see the future?

Categories generated by answers in response to this question and the frequency with which they were reported are shown below in Table 5.

With little change	9
Very uncertain	4
Question difficult to answer	3
With dread	3
Hoping children will stay sane	3
Taking one day at a time	2
Sad	1
Hoping for improvement	1
Getting more difficult	1

Table 5: Categories and frequency with which they were described generated from answers to the question "How do you see the future?"

Two broad themes emerged from these categories.

i) Realistic expectations.

"I can see the tensions building up, increasing demands making life busier, especially if we just want an ordinary family life. There will always be extra demands on me requiring a lot more effort just for an ordinary life."

ii) Uncertainty and denial.

One woman said that she does not want to think ahead:

"sometimes I can see light at the end of the tunnel but often the curtains are drawn. I'm 25, and I've got no kids, I'm not married and I wonder if I'll ever get those things. I block out what lies ahead."

Abstract concept developed from these questions

Characteristics of the relationship seen as positive range from commitment and companionship to ambivalence. Spouses visions of the future can be described as being on a continuum between a denial and realism but weighted at the denial end of this continuum. The detachment with which many of the women answered these questions was striking. It appeared to be a necessity that they denied their emotions, just plodding on, yet with no hope or compensating factors. Building on findings from the previous questions which indicate that the relationship has changed in ways that are negative and the struggle of daily life, perhaps it is less painful for some of the women to deny their losses and try to block out thoughts about the future.

3.2.5 Female partners' views of the support/help they received

Qualitative Exploration

5.1: What opportunities have you had for help or support through statutory services?

Categories from answers to this question are shown below in Table 6.

Offered no formal support (Headway excluded here)	14
Self-referral to Relate (reported unhelpful)	3
Psychology	1
Awaiting psychology appointment	1

Table 6: Categories from the answers to the question "What opportunities have you had for help or support through statutory services?"

Linda said:

> "People just seem to ignore the sexual side of things and don't even ask. For us, the more its been ignored the more of an issue it has become. Even when I went to the GP after my last baby he prescribed the Pill for me and I couldn't even tell him that there was no point in me having it so I accepted the prescription."

5.2: What would you have liked in terms of support?

Categories are shown below in Table 7.

Long term help (counselling or therapy)	6
Someone to listen to their side of things.	2
Family therapy	2
More information about head injury	6
Don't know	4

Table 7: Categories generated by answers in response to the question "What would you have liked in terms of support?

The main theme was that most women would have welcomed help of some kind.

Linda specifically recommends that if wives can possibly afford it they should seriously consider seeking help, even if that means paying for it privately. Although it took a lot of courage to take the first step, for her it has been invaluable. Emma also saw a psychologist privately which she said was helpful.

3.2.6 How it felt for female partners to take part in the research

Qualitative Exploration

6.1: How did it feel to take part in the research ?

Categories are shown below in Table 8.

Okay as it's something worthwhile	10
Therapeutic	11
Sobering	9
Sad and reflective	8
Made me realise how abandoned I've been	1
A bit difficult to answer personal questions, uncomfortable - but still answered them	3

Table 8: Categories from answers to the question "How did it feel to take part in the research?

Answers to this question form part of the evaluation for the study. Sophie felt that the questionnaires about sexual relationships were very important given that it is an aspect that has changed since the injury. For the majority of women,

taking part in the study was reported as therapeutic. None expressed regret at having taken part. Three women wanted follow up phone calls from the author.

3.3 Miscellaneous and post hoc findings

Items of GRISS subscale scores after injury.

These are shown below in Table 9.

Subscales	No. of women who scored over 5
Female avoidance	11
Dissatisfaction	3
Non-communication	10

Table 9: Scores from subscales on items from GRISS

Eight out of seventeen women scored 5 or more in two out of three subscales and two out of 17 women scored 5 or more in all three of the subscales. According to normative data, when the GRISS is administered as a whole a score over 5 within each of these subscales indicates the presence of a problems in that subscale, although one score over 5 would be expected and acceptable.

3.4 Summary of quantitative findings

The following hypotheses were supported by the results:

Hypothesis 1.1: There will be a difference in womens' reports of marital state before and after husband's injury.

Hypothesis 1.2: There will be a difference in womens' reports of aspects of sexual satisfaction before and after husband's injury.

Hypothesis 2.2 b): There will be a relationship between perceived mens' coercive sexual behaviour and womens' ratings of sexual satisfaction.

Hypothesis 2.4: There will be a relationship between womens' reports of husbands sexual advances being welcome and female avoidance of having sex.

Hypothesis 3.1: There will be a difference between womens' and mens' reports of aspects of current marital state.

CHAPTER FOUR

DISCUSSION

4.1 Discussion of method

4.1.1 Recruitment

The sample size in the present study was small which has implications for the robustness of findings. The reason for the sample size being small was the strict inclusion criteria for the study. It was felt that this would have the advantage of allowing an intense study with a narrow focus on a small group, thus increasing the generalizability of the findings. However, this led to problems in recruiting participants, despite attempts to recruit from the best access points across the south-east region (rehabilitation services and Headway).

One way of trying to overcome these constraints would be to recruit via the same sources over a larger geographical area; another way would be to increase the sources through which participants were recruited, such as tracing through Accident and Emergency services and other rehabilitation services. This would seem particularly important given that some coordinators of Headway branches stated that there were many relatives and spouses of people who had sustained head injuries who had only made "one off" contacts with them, but who were not actually members. Personal details of such people were therefore not available. Also, some participants in the present study stated that, for various reasons, they chose not to have contact with Headway.

4.1.2 Biases in sample

Participants who responded to their initial contact letter and went on to take part in the study were likely to belong to a group of people who were particularly willing to verbalise their experiences. The fact that some of the women stated how they had to vocalise their wishes and partners' needs very emphatically in order to get certain services suggests that this subgroup

might have been more vocal then others: vocal people may be more represented among those who have had rehabilitation or are involved with Headway. Couples who were unwilling to take part may have offered different information; couples who were not contacted because they were not accessible via either rehabilitation services or Headway may have offered a different perspective again.

4.1.3 Conducting interviews

This was seen as important for two reasons. First, the sensitive nature of the study could have been distressing for participants and so it was considered appropriate to give the questionnaire part of the interview in the presence of the researcher. At the beginning of the interviews rapport was built with each couple which may have shaped their willingness to offer such substantial amounts of information, but more importantly helped to build trust and a 'safe', containing experience for them. Second, it was felt important as a way of attempting to get maximum standardisation and accuracy of responses from the participants: some participants asked questions about the meaning of particular words. The presence of the researcher meant that clarification could be given where required, although care was taken not to bias their responses. Research using postal methods sacrifices accuracy and standardisation, such as omission of questions and ensuring respondents can complete questionnaires with minimum distractions.

The other reason that personal contact was felt to be important was because it allowed for open questions to be asked more easily and facilitated inclusion of a qualitative approach. Most important, however, was the fact that if any of the questions elicited distress in the individuals then the clinical skills of the author could be drawn on to attend to these. This highlights the importance of research interviewers being trained to use clinical skills.

4.1.4 Qualitative versus quantitative methodologies: strengths and weaknesses

As can be seen from the results section, implementing a qualitative approach has offered a richness of information to compliment the quantitative results. The author believes that a quantitative approach alone would not have yielded the depth of insight which this study has elicited. The quantitative component started with testable hypotheses incorporating measuring tools with standards of validity and reliability. These concepts are different when considering qualitative methods; traditional scientific approaches often question the validity and reliability of qualitative methods. As described in the method, auditability with regard to objectivity, respondent validity and inter-rater reliability have been used to guide the evaluation of this component.

Auditability with regard to objectivity

Citing Harding's (1991) distinction between weak and strong objectivity in science, Henwood and Pidgeon (1995) state that:

> "Weak objectivity occurs when the inevitable layers of subjectivity are over-written or obscured. In moving towards a strong objectivity, the researcher makes public the full range of interpretive processes involved in knowledge production" (p.118).

In attempting to meet stronger objectivity, the method section gives a full explanation of this process and the quotes which were grouped into categories are presented in appendix 26. This allows others to scrutinise the data and so increases the auditability of this component of the study. It is acknowledged that the open questions themselves introduced themes which were likely to have influenced the answers people gave but are unlikely to have influenced the

categories and themes which emerged to any great extent. The questions asked were as open as was felt possible, indicated by the amount of material generated. In qualitative explorations the investigator is part of the construction that is arrived at as the researcher's biases can never be entirely removed.

Respondent validity

The debriefing question on how it felt to take part in the research indicates that the interviews were therapeutic for the women; this in itself makes the research valuable. However, given the power dynamics involved between researcher and participant, Silverman (1993) questions how reliable participants' feedback might be. Respondent validity, by asking participants for feedback and comments on qualitative findings, would be one way of finding out how valid the participants felt the information was. A report of the findings is currently being prepared for participants and comments will be invited in response. The author intends to offer a presentation of the findings to Headway groups, which will give further indication of its value.

Inter-rater reliability

This was shown to compare closely with the author's findings.

4.1.5 Discussion of Quantitative Measures

Ratings on the GRIMS and items of GRISS relating to before the head injury occurred, involved retrospective data gathering. Because by definition this relies on retrospective memory, the reliability of responses is called into question. However, it was felt that the womens' subjective experience of their previous relationship was important. One way of trying to increase the reliability of the results would be to modify the design by increasing the number of participants,

or, include a comparison group so that retrospective data gathering would be uneccessary. A suitable comparison group would be couples where the men have survived a traumatic accident but not incurred cognitive impairment, such as in spinal cord injury. Following discussion about this, a decision was made not to include a comparison group because of the absence of a specialist rehabilitation centre with reasonable access in the south-east region.

GHQ

This measure gave a good indication of participants' emotional well-being at the time of the interview, but as a measuring tool, it fails to identify the fluctuations of changes in this variable over time. However, given that it is a commonly used research tool within this area, it allows for comparison studies to take place. Three of the women stated that at around one year following injury they felt the most distressed and yet research indicates that emotional well-being does not improve over time (Brooks *et al.*, 1986).

Injury-Related Symptoms Questionnaire

Participants found this a lengthy questionnaire to complete and five of them asked the author the meaning of some of the items and words used. For example, 'responds to social cues' and 'is sexually disinhibited' were unclear to some people. Again, the advantage of the researcher being present was that clarification could be given; this maximised the chances of the questionnaire being completed with greater accuracy by participants. Although reliability of this measure was found to be positive it was only moderately so, indicating that findings using this measure should be treated with only a moderate degree of certainty.

GRIMS

A few participants commented on the fact that responding to items on this questionnaire was difficult because of a forced choice to either agree or disagree with no 'in-between' response to choose from. The head-injured men were asked to complete only eight items of the GRIMS which meant that scores could not be compared with normative data, however, it did allow comparisons with the same items answered by their wives. The reliability of this measure was found to be high.

Items from GRISS

That only eight items of the GRISS were used in this study did not allow for comparisons with normative data on the full sexual satisfaction scale. However, a decision was made to use items which were appropriate to the area under investigation and limitations on findings posed by this decision were felt to be acceptable. Furthermore, reliability was found to be high. The items used in the study comprised two full subscales and half a subscale from a total of seven subscales that comprise the GRISS. It was felt that these offered adequate data for the nature of the study and to include the entire questionnaire, despite the facility of comparison with norms that this offers, would have been inappropriate because of the lack of relevance and the intrusiveness of the items. Furthermore, had the whole GRISS been given this might have compromised participants' willingness to engage in the remainder of the interview in the way that they did.

When answering the items from the GRISS concerning the current relationship, those women who reported that there was no sexual relationship omitted a number of the questions because they were not applicable. This meant that although the sexual relationship was non-existent for those participants, when their scores were totalled they were lower than they would have been if a

sexual relationship did exist because the item would then have been applicable and giving an answer would have been possible. Therefore, this will have shaped the outcome of results in that they may be rather more conservative than was actually the case: where there was no sexual relationship at all since the injury scores will be lower, yet with the GRISS items the higher the score, the greater the problem in the sexual relationship. Of course, this is assuming that a lack of a sexual relationship is problematic; for all but one of the participants who experienced a lack of or reduced sexual relationship this was indeed problematic. Another factor that will have made scores lower, indicating less problems, is the responses given to items comprising the subscale 'avoidance'(items four to eight of the aspects of sexual relationship questionnaire). Again, where there was reduced sexual activity participants rated these items in a way that would have produced a lower score. For example, in response to the question 'do you ever try to avoid having sex with your partner?' was answered by some participants as 'never' (a score of 0) because, as they explained, they did not wish to avoid something that they wanted, which was an infrequent occurrence anyway. This may have impacted upon some results producing non-significant findings.

Relationship Change Questions

This was commented on by a number of participants as feeling the most relevant questionnaire for them in the study. Based on the experience of senior clinicians in the field, it seemed particularly relevant for many participants. However, item six only elicited limited information: the statement read 'my partner is just as interested in our sexual relationship now as before the injury' and possible responses were 'yes, definitely; yes, somewhat; no, not so much; no, not at all.' Unfortunately, there was no response to indicate an increase in sexual interest and participants for whom this response was applicable gave the response 'yes, definitely.' This meant

that in using the questionnaire alone in the analysis, this data would have been obscured. For this reason when analysing this variable, verbal reports were included to complement the ratings elicited from the questionnaire. Ideally, in view of this, an additional item "my partner makes more frequent sexual advances towards me since the injury" would have been helpful in generating quantitative information.

A further problem with this questionnaire was that because the rating scale only had four points it did not allow for a wide range of scoresto be incorporated in the correlational analyses.

4.2 General discussion of findings in the context of previous research

4.2.1 Changes in couple relationships since injury as reported by female partners.

Marital State

It is estimated that less than one third of couples are thought to stay together by two years after injury (Anderson-Parente' *et al.*, 1990), indicating the high level of distress in relationships after TBI. In the current study, although the inclusion criteria specified that couples should still be together, a high level of marital distress was reported and a significant difference was found in female reports of marital state before and after husband's injury, changing from 'good marriages' to 'marriages with severe problems' (hypothesis 1.1). The extent of injury-related symptoms was not, however, found to be associated with marital state, but the reliability for this measure was found to be moderate, perhaps accounting for this non-significant result (hypothesis 1.3).

Drawing on information from the qualitative component the biggest changes reported by wives were characterised by multiple losses. These tended to be related to aspects of the relationship previously seen as positive: an equal partnership and companionship; intimacy; closeness; and

emotional support. These components of relationships were much reduced since injury in the sample group suggesting a lack of mutual support and reciprocity. Some relationships also had the extra strain of husbands' unpredictable mood swings. These findings are consistent with reports from Serio *et al.* (1995) who comment that 'a wife whose husband sustains a brain injury often loses her confidant, sexual partner, economic support, household co-manager and child rearing assistant. Spouses express discomfort with a very dependent husband, especially when his maturity level seems less than that of their young children' (p.42). This was identified as an important element in the current study.

Changes in roles were perceived as the biggest change, with all eighteen women reporting that their role had definitely changed since the injury. The additional responsibilities, such as decision making and going to work full time, made greater demands on the women, as did 'becoming more like a mother than a wife' to their husbands. For some women, particularly those who had described themselves as passive before their husband's injury, these greater demands forced them to 'grow up.' That this process of 'growing up' was seen as being forced upon them suggests that it may have been experienced by them as less than positive. In fact, given the great strain reported by participants at various times since the injury occurred, it is argued that most of these additional features in the relationship since injury have been experienced as negative. Even in those relationships where husbands were capable of helping with domestic tasks, thereby making a contribution to family life rather than solely being cared for, wives still felt huge responsibilities and felt they were in the role of carer. This was the case with at least three couples where husbands helped with parenting duties.

That no relationship was found between female reports of current marital state and emotional

well-being was unexpected (hypothesis 1.5). It is possible that this was due to a ceiling effect on both variables. The GHQ scores showed that 61 per cent of women in the sample had a level of emotional distress that is consistent with clinical 'caseness'. Futhermore, the emotional strain reported in response to the open questions offer evidence of the presence of distress. Scores from the GRIMS showed that sixteen out of eighteen of the women rated their marriages as 'poor', 'bad', 'with severe problems' or 'very severe problems' after the injury. Clinically, this finding is important. Additionally, the qualitative data suggests that these women were denying some of their feelings, perhaps making this finding less of a surprise.

So what do these spouses get from being in relationships which have severe problems and why are they still in the relationship? Do they deny their own emotional needs? Despite all the losses, many women stated that they 'just get on with everyday life' and many were open about having given little expression to their grief by 'putting up barriers so I can stay strong', suggesting that they were denying many of their emotional needs in order to get from one day to the next. To illustrate the magnitude of how demanding daily life, is one participant offered a piece of information that demonstrated this poignantly: at the end of the interview she disclosed that she had been sexually abused as a child. She said that she was aware that this had caused her a variety of long-term psychological effects and yet because her life was so hectic now, it was low on her list of priorities to seek help about these.

Clearly, there are no straightforward solutions for partners in this situation. Perhaps Rosenbaum and Najenson's (1976) suggestion of 'good adjustment', with women switching roles from partner to carer, is the only possible adaptation if partners wish to stay within the relationship. However, it is debatable whether partners are able to distance themselves effectively and for how long, and

at what cost to their own emotional well-being. These factors may depend on personality and coping style of the partner. The present study indicates that the price is high.

Whether there was a relationship between female spouses perceiving their partners as more dependent since injury and marital state could not be tested because seventeen out of eighteen participants reported their husbands as being 'definitely more dependent' and the eighteenth reported her husband to be 'sometimes more dependent', so producing a ceiling effect (hypothesis 1.4, a). This is an extremely important finding given that all responses indicated an increase in husband's dependency. The same was true when trying to test for a relationship between female spouses perceiving their partners as more dependent since injury and emotional state (hypothesis 1.4, b).

Sexual satisfaction

The current study found a significant difference in spouse reports of aspects of sexual satisfaction before and after husband's injury in the direction of lower satisfaction after the injury (hypothesis 1.2). It is possible that the scores representing the sexual relationship before injury have been influnced by the demographic variable of length of time the couple had been together (as shown in results), but given the significance level of the result for hypothesis 1.2, this is highly unlikely to have had a large enough influence alone to make the finding as significant as it is. Rust and Golombok (1986) suggest that 'it is to be expected that a normal relationship would give at least one score of 5 on the subscales, which need to be interpreted as a whole' (p.21). Unfortunately, it was not possible to interpret this as a whole because only a limited amount of subscales were suitable for use for the purpose of this study. Despite this, almost 50 per cent of women scored 5 or more in two out of three subscales, and almost 10 per cent scored 5 or more in all three of

the subscales. These findings indicate dysfunction in 60 per cent of the sample. However, the reported changes the sexual relationship may be of minor importance when set against the wider scheme of things in daily life and the extra demands described above.

Within specific subscales: over 50 per cent of women had scores of 5 and over in avoidance of sex, 50 per cent had scores of 5 and over in non-communication about their sexual relationship, and in the area of dissatisfaction (where only two of the four items which comprise the scale were used) 11 per cent scored 5 and over. This is a first step towards confirming Lezak's (1976) suggestion that after a man has had a severe head injury, their partners seldom have their psychosexual and affectional needs satisfied and confirms that women spouses experience significant changes in the areas covered by the subscales.

One explanation for these changes comes from the qualitative data. The three women who felt that they were more like mothers than partners to their husbands felt uncomfortable when relating sexually to them: such a perception is likely to inhibit sexual relationships. Although not specifically referring to the sexual relationship, four other women said that they felt their husbands were like children. Others reported that their sexual relationship was boring and that head-injured partners were self-centred in their sexual interactions.

4.2.2 The impact of personality change after TBI on aspects of marital state and sexual satisfaction.

The degree to which spouses perceived their husbands to be less interested in their sexual relationship confirms the suggestions made by Zasler (1991) that a decrease in interest is common in men after TBI. In fact, Blackerby (1987, in Ducharme and Gill, 1990) reports that as many as

three-quarters of all head-injured survivors experience decreased frequency of sexual relations. Although the current study did not explore frequency of sexual interaction, the notion of interest may offer indicators of this. No difference was found between reported levels of male sexual interest and spouse ratings of current marital state (hypothesis 2.1, a); nor was a difference found between reported levels of male sexual interest and spouse ratings on aspects of sexual satisfaction (hypothesis 2.1, b). These two findings suggest that level of male sexual interest is not viewed as problematic enough to be associated with marital or sexual satisfaction, suggesting that other factors are likely to be associated with these variables. Perhaps, as Lezak (1976) suggests, it is easier to live with a sexually uninterested partner than one who is more interested. However, given that some of women in this sample expressed a wish for more sexual interaction with their husbands, the findings of the current study do not wholly support this. Furthermore, the qualitative findings indicate that often, the women did not know what their partners' feelings were, so when they do receive demonstrations of affection and intimacy from them they are likely to feel confused and ambivalent.

Where husbands were perceived as sexually coercive there was a significant relationship between this and spouse ratings of sexual satisfaction, indicating that higher perception of husbands' coercive sexual behaviour was associated with lower spouse sexual satisfaction (hypothesis 2.2, b). It is important to note that sixty per cent of the sample group felt sexually coerced to varying degrees by their husbands since the injury. This finding could be an explanation for Lezak's (1976) suggestion about living with a sexually uninterested partner, although these findings are difficult to interpret because coercion includes interest, but with an additional element of pressure, threat or manipulation. Perceived sexual coerciveness was not found to be associated with marital distress, indicating coerciveness as having a specific effect on sexual satisfaction as would

be expected. This is a finding which helps to explain the lower level of overall female sexual satisfaction post-injury. A highly significant relationship was found between spouse reports of husbands' sexual advances being welcome and female avoidance of having sex, confirming that the more unwelcome the husbands' sexual advances the greater their wives' avoidance of it (hypothesis 2.4).

No relationship was found between spouse perceptions of their partner as a stranger and spouse ratings of marital distress (hypothesis 2.3, a). The same was true of a relationship between spouse perceptions of their partner as a stranger and spouse ratings of sexual satisfaction. Yet ten out of the eighteen women reported that their husband had felt like a stranger to them since the injury (eight said 'yes, sometimes' and two said 'yes, definitely'), which suggests that, as in the Anderson-Parente' *et al.*, (1990) study this change may not have been seen as entirely negative. Maybe one way of coping is for them to actively deny the presence of the person who used to be; therefore, actually perceiving them as a stranger may be adaptive in allowing them to become caregivers.

4.2.3 Partner's perceptions of the relationship.

Following TBI, the lack of awareness and insight in the injured person is likely to result in their perceptions being quite different from their partners' (Brooks *et al.*, 1987). In terms of how they view their marital relationship this was indeed found to be the case: a significant difference was found between female spouses' and husbands' reports of aspects of current marital state with wives reporting more marital distress than husbands on the same eight items from the GRIMS (hypothesis 3.1). Other research in this area has identified that patients under report difficulties compared with relatives (Brooks *et al.*, 1987). This indicates the problems for couples in trying

to negotiate anything at all and highlights the probable frustrations experienced by both when they are unable to appreciate one another's points of view.

It was salient from the qualitative data that some of the women were attempting to put together pieces of a puzzle to make sense of their confusion about their husbands' feelings for them. This left them guessing and trying to arrive at explanations about how their husbands felt. Other women were in no doubt about their husbands' feelings; yet even when these were feelings of affection, this was not always felt as a mutual exchange because it appeared to be related more to their husbands' lack of awareness that change had indeed occurred since the injury. In the Anderson-Parente' *et al.* (1990) study, the authors suggest that couples who stayed together perceived that the other still cared for them. This was less so in the current study where feelings of gratitude were prominent and not totally welcomed by the spouses. Verbal responses such as 'I think he loves me', 'I don't know what his feelings are' and 'he never shows me any affection' demonstrate much uncertainty.

4.2.4 Aspects of the relationship women felt were positive after TBI and how they see the future. These questions were an attempt to glean some clues as to what the reasons were for couples staying in their relationships, despite the presence of severe problems in their marriages. That one third of the women responded with a long silence and a sigh before answering this question indicates that it was particularly difficult for them to answer. Characteristics of the relationship that were seen as positive ranged from commitment and companionship to ambivalence about whether or not there was anything positive in the relationship. This differs from the findings of Anderson-Parente' *et al.*(1990) who found that couples who were still together focused on the positive side of their relationships and that carers viewed their spouses with warmth and respect,

not as a burden.

Given the enormity of loss, what were the compensating elements that, from the womens' points of view, made it worth their while to stay? The answer seems to lie in the areas of commitment and companionship. These concepts can be seen as having negative and positive connotations attached to them: commitment may be perceived as obligation, responsibility and duty, whereas companionship, (where it still exists) suggests a more give and take relationship, involving qualities of friendship.

Spouses' visions of the future can be described as being on a continuum between denial and realism but heavily weighted at the denial end of this continuum, and 50 per cent of women anticipating that things would 'stay the same'. This was accompanied by little hope or comfort. It is concluded that many of the participants in the study continued with the demands of everyday life and coped by detaching themselves from the pain of the experience. Additionally, it is likely that the demands of everyday life outweigh the difficulties in relationships identified in the current study.

4.2.5 Womens' views of the support/help they received.

Feelings of being let-down by services dominated the experiences of women. One third of them expressed dissatisfaction about care in the acute services saying that they had to assert themselves emphatically in order to ensure their husbands received the care to which they felt they were entitled.

In terms of long-term support and help, participants were even more disappointed, with most of

them being offered no professional input to help them cope with their relationship, or how to cope with a changed person as a partner. Feelings of abandonment were strong and women expressed the need for 'just someone to listen to my side' to more formal help in the form of family therapy. This resonates with reports in O'Carroll *et al.* (1991) which stated that out of 122 individuals who were sent recruitment letters for taking part in a study, only seven had received any form of follow up care. Those who did seek help from services such as Relate found them to be well intentioned but unhelpful in that they were not able to offer the specialist help without knowledge about head injuries.

4.2.6 How it felt for the women to take part in the research.

Given that participants felt so abandoned by services and also were experiencing a level of emotional strain, it is perhaps unsurprising that so many of them found it therapeutic to take part. This finding in itself is an important evaluation of how helpful it was for participants to be able to tell their story; many of them found themselves able to offer much information and some commented that they could have talked for longer. This has implications for future research in that the interview process itself can be therapeutic for participants.

4.3 Clinical implications

This research highlights that relationship issues and exploration of partner's responses to living with a head injured person should be just as much a part of rehabilitation services as other aims. Yet partners commonly find very little opportunity to discuss their deliberations and uncertainties of their options for the future. Some women in the present study felt unable to raise the subject of problems in their relationships to anyone at all. The need for support for spouses is highlighted by these findings and, if provided, it could be a way of helping them strive for a better quality of

life after TBI. This might include helping them find ways of coping emotionally, or how to avoid not being sexually coerced, and perhaps facilitating informed decisions as to whether they want to continue in the relationship, then supporting them in the decisions they make. In an inherently difficult situation, it would be simplistic to suggest that by offering support services to partners of head-injured people would make life acceptable for them: indeed, it may be more realistic to facilitate a reasonable ending, if they choose to leave the relationship.

The timing of interventions would be important: too early and it may be inappropriate and not seen as a priority, too late and an intervention may be of little use. Of course, working therapeutically with partners raises ethical considerations such as who the client is, and clinicians need to anticipate and contemplate such issues.

Regarding the sexual relationships, Zasler (1991) explains that a person's sexual functioning is 'a mode of cementing the emotional bond with the person's sexual partner. When this capacity is diminished or disrupted, psychological implications can range from minor to catastrophic depending on the individual's situation and history' (p.14). Zasler (1991) advocates open discussion of these issues saying that one of the largest contributions that the rehabilitation professional can make to help a person adjust to their illness or disability is to talk to them about it. This can also be applied to partners of head-injured people and it is argued that the process of carrying out the present study made such a contribution.

These issues emphasize the importance of considering relationships in rehabilitation settings and an important next step will be to share these findings with services providing care for people with head injuries. Zasler and Horn (1990) recommend that although it should be remembered that

sexual relationships are not an issue for everyone, couples should be asked what their specific concerns are regarding the importance of their sexual relationship. Importantly, they also advise that sexual preferences need to be identified and not assumed.

4.3.1 Service level

That no women in the present study were routinely asked about sexual relationship issues points to several possible explanations. Perhaps there is a lack of recognition of these issues by services or an avoidance of addressing them. Indeed, there appears to be little training, formal or informal, concerning sexuality for rehabilitation professionals involved in the care of TBI survivors (Davis and Schneider, 1990). Zasler and Horn (1990) argue that rehabilitation staff should be obliged to provide their service users with information as part of an ongoing sexual rehabilitation programme. Ducharme and Gill (1990) speculate why staff avoid discussions about sexuality and suggest that most people feel anxious regarding sexuality. Combined with fears that talking about sex with head-injured people will lead to sexual inappropriateness, it is seldom addressed. Also, they suggest that people with head injuries are stereotyped as asexual or hypersexual. Staff training seminars with the aim of providing information and increasing confidence in discussing relationship issues would be helpful. Ducharme and Gill (1990) and Blackerby (1990) describe approaches in which consultancy, individual and group therapy programmes, in-service training, and establishment of a sexuality committee to oversee policy development take place. This is already addressed in a number of learning disability services (Craft, 1994).

It can be suggested that rehabilitation organisations cope with their own distress of such painful situations by denying it and therefore some of the most distressing elements of brain injury, such

as the profound losses for all involved, do not have to be brought to consciousness and acknowledged. As an individual might deal with painful issues by denying them, like many of the women in the present study, so too can the wider system and organisations (Menzes, 1970).

4.4 Future research

A number of questions are raised by the findings in this study. Perhaps those women that do not or are not prepared to deny their own feelings are less able to stay in such relationships. Comparison studies between women in couples who have stayed together, and those who have separated, could shed light on this. Also, would those women who had a difficult sexual relationship with their husbands, because they seemed more like sons, find the relationship more acceptable if their partner felt more equal to them. Or did they anticipate that this was unlikely and so wish for a sexual relationship with someone else?

It would also be interesting to explore any differences in partners' distress in relation to the time since injury. For example, data from the present study could be explored for differences between womens' emotional well-being at one to three years since their husbands' injury with four to seven years since injury.

Further research could explore possible gender differences in the findings from the current study; one way of addressing this would be to use a comparison group focusing on male spouses where women have had a head injury. A number of differences have been found in men and women as carers of relatives with dementia (Zarit *et al.*, 1986); for example, men were more able then to distance themselves from the demands made on them.

4.5 Conclusion

There are many complex reasons why relationship problems occur after severe head injury: the personality changes in the head-injured partner, the high levels of strain experienced by spouse carers, as well as reduced income from loss of earnings, can each contribute to the worsening of the marital and sexual relationship. The current study shows more variability in female partners' responses to the changes in the sexual relationship after the injury than the literature suggests. Despite few rewards to balance the challenges, spouses seemed largely committed to staying in their relationships. It is reasonable to suggest that, to a large extent, their ability to stay in the relationship is related to their ability to distance themselves from their feelings. Perhaps those women that do not or are not prepared to deny their own feelings are less able to stay in such relationships and make a decision to leave or separate.

Partners of head-injured people face excruciating decisions around how to create reasonable lives for themselves. They often find themselves quite alone in this process as few others may appreciate the nature of the problems they face. In the light of the high incidences of marital and sexual relationship disturbance observed in this and other studies, proactive and systematic follow up of head-injured people and their partners is recommended. Where problems are identified, early enough intervention might prevent further deterioration. Untreated, such problems can lead to chronic relationship distress.

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Appendix 1

Dear

I am writing to ask for your help in a research study. This is to look at how a head injury can affect marriages/partnerships. This is being carried out by Jo Gosling under my guidance.

I enclose a letter from Jo about the study and I should be very grateful if you would agree to help.

Of course, the results of the study will be anonymous and no personal details will be disclosed.

Kind regards.

Yours sincerely,

Dr Michael Oddy

Consultant Neuropsychologist

Appendix 2

Dear

I am a psychologist in clinical training currently working with Dr Mike Oddy at Ticehurst Hospital Head Injury Rehabilitation Unit. I am currently contacting a number of couples (each partner separately) who have had links with Ticehurst. I am writing to you in the hope that you may feel able to help me with a research study I am about to undertake.

I have attached an information sheet to give you an overview of the study and explain what taking part would involve. Two weeks after you receive this letter I would like to make telephone contact with you to discuss the project in more detail. I will be keen at this stage to answer any questions you may have. This conversation may help you to decide whether you wish to participate further in the work. If, however, you feel certain now that you will *not* wish me to contact you at all please return the slip attached in the Freepost envelope provided within the next week.

I do hope you feel able to support this work and would like to thank you for taking the time to read this letter. Please feel free to contact me if you have any further queries via either of the following numbers:
Yours sincerely,

Jo Gosling

I do not wish to be contacted about this project.

Name (please print).....

Appendix 3

Information about the study

Title of the study
Marital couple relationships and emotional state following traumatic brain injury.

About the study
The study will explore the possible changes and emotional effects which people may experience in their relationship with each other following a head injury. It will focus mainly on the feelings and experiences of women whose husbands have suffered head injury. This is an important project which may help to improve our understanding and influence the way services are provided.

What participation will involve
I will see each partner on their own in their home and discuss the project in more detail with them. I will ask the female partner to complete a number of questionnaires on her own. These will look at issues arising since her partner was injured, at her emotional well-being and at the quality of marital and sexual relationships; I would also like to ask a few questions and, with permission, I would like to tape record the answers to these. I expect this to take around one and one-half hours to complete. During this time I will ask the male partner to complete a short questionnaire on his own which will take about ten minutes to complete. This will look at his feelings about the relationship and I will offer any help he may need to complete the questionnaire.

I am also keen to know how it felt to participate in the study so at the end of the visit I plan to ask about this. You will also be given phone numbers for local support services (where appropriate) should you wish to talk about any issues that arise. I will offer a follow-up telephone call to participants two weeks after my visit to check how they are and answer any questions they wish to ask.

Your rights if you take part
Participation in this study is voluntary. At any time during the study you have the right to end your involvement; you also have the right to omit any questions you do not wish to answer. If you decide to take part I will ask you to sign a consent form and I have enclosed a copy of such a form so you can see what it involves. A decision not to participate in this study will in no way affect any treatment you currently receive or may want in the future.

After the material is collected
All material will be for the purpose of this research study only. All identifying information will be kept in strictest confidence and be treated as anonymous. Any tape-recorded information will be erased as soon as the study has been completed. Participants will receive a summary of the results of the study one month after its completion if they want this.

Appendix 4

STANDARD CONSENT FORM WHERE THE SUBJECT IS CONSENTING ON THEIR OWN BEHALF

Name of Subject: _____

I, _____ (investigators name and title)

of _____ have fully explained to this subject the nature and

purpose of the research project entitled:

and they have consented to participate. I have given them a copy of the information sheet about this research project and have answered their questions. They have kept the information sheet for future reference.

Signature of Investigator: _____ Date: _____

Name (in capitals): _____

I (name): _____

hereby consent to take part in the above investigation, the nature and purpose of which have been explained to me. Any questions I wish to ask have been answered to my satisfaction. I understand that I may withdraw from the investigation at any stage and this will in no way affect the care I receive as a patient.

Signed

Subject: _____ Date: _____

Appendix 5

Brief for telephone call following receipt of reply slip giving permission for me to do so.

Thank you for returning the slip.

The purpose of this call are:

1. To give you an overview of the study clarifying what is on the information sheet.

2. To tell you what it involves: there are some questions that I would like to ask everybody, but I would like to spend more time talking with the women in the study.

3. To answer any questions you might have and explore any concerns you may have.

4. To ask if you agree to taking part and, if so, arrange a date for this.

Appendix 6

Dear

I am a psychologist in clinical training currently working with Dr Michael Oddy based at Ticehurst Hospital Head Injury Rehabilitation Unit. I am currently contacting a number of couples (each partner separately) who have contact with Headway to ask for their help with a research study I am about to undertake for my Doctorate in Clinical Psychology.

I have attached an information sheet to give you an overview of the study and explain what taking part would involve. As the next stage, I would like to ask you for permission to contact you by telephone to discuss the project in more detail. If you are in agreement with me 'phoning you please return the attached reply slip in the enclosed Freepost envelope; I shall only contact you if I receive the reply slip. As I am hoping to proceed quickly with my work could I ask you to return the slip *within two weeks* if you decide to do so. Our conversation may then help you to decide whether you wish to participate further.

I hope you feel able to support this work and would like to thank you for taking the time to read this letter.

Yours sincerely,

Jo Gosling

Psychologist in Clinical Training with
Dr Michael Oddy, Consultant Neuropsychologist

I have read the letter and the information sheet. I agree to you contacting me about this study.

Your name .....

Your 'phone number .....

Appendix 7

Emma and Daniel

Emma, a teacher, and Daniel, a dispatch rider, had been in a stable relationship since they were fourteen years old. They have three children whose ages at the time of the accident were six months, two years and three years. Daniel's injury happened five years ago when he was riding pillion on a motorbike. His severe injury has turned the family life upside down and Emma says she has gained a fourth child instead of still having a husband. However, she has also had to cope with being sexually harassed by her husband since the injury which she considers to be even more opressive than if she were being physicalyl abused.

Robyn and Charlie

Robyn, a nurse, and Charlie, who worked in a bicycle business, had two children ages two and six when Charlie had a cycling accident three years ago. Before the accident, their relationship 'had lots of fun and silliness'. Robyn said that had not felt able to disclose her disappointment in the lack of a sexual relationship with her husband to anyone previously. She was deeply empathic about Charlie's injury. 'having had a head injury must be a living hell - you look the same to others yet you're different.' Now she says she just keeps going for the children, 'putting up barriers' to stay strong. As will be described in the results section, their life has been thrown into disarray.

Linda and John

Linda and John had been together in a stable relationship for three years when John had his injury; after a year of being together they had married and were looking forward to having a family in the near future. This event and all its importance for Linda had not been able to come to fruition. John, whilst riding pillion on a motorbike, suffered a severe head injury when a car pulled out in front of the bike. On the day of the accident Linda and John had been in the midst of replacing their bathroom suite having not lived in their home for very long, so their home was in chaos. That was four years ago and since then life has been extremely challenging for them, with their own parents trying to be involved and yet this in itself causing tensions within the family.

Pam and Tom

Pam and Tom were married for twenty years and had two children, one of whom was living at home. Two years ago, when Tom was a car passenger travelling to spend the day fishing, he suffered a head injury when a car in the opposite side of the road was out of control and collided with the car. Pam's mother, whose health was in decline, had moved in with them. When Tom was due home from hospital Pam knew she could not cope with both of them together and eventually her mother had to go into a nursing home and has since died. From Pam's account their relationship prior to the accident was not one which she found emotionally supportive, but they had been committed to the relationship. The biggest difficulty for Pam since the injury is trying to cope with Tom's unpredictable and explosive temper.

Sophie and Alistair

Six years ago Sophie and Alistair were on a waiting list to adopt a baby. Eventually, they were informed that a newborn baby was considered suitable for them to adopt. Alistair drove to London to see the baby but on his return, another vehicle which was out of control collided with his and he sustained a severe head injury. Days after the accident Sophie was coping both with

a new baby, making adjustments to being a mother for the first time and with her husband in a coma. Sophie reported that had she not had a medical background and sought out information the psychological support she had asked for would not have been offered and that someone with less confidence would not have been able to request it. Her descriptions of the changes in their relationship in itelf were extremely powerful, although she attributes a lot of the strain in the early stages of Alistair's recovery to the fact that they were also adjusting to being new parents. They have since had another child of their own, now three. In the sixth year post injury, Sophie felt that things were still gradually improving for them. Of all the narratives, this one was considered by the author to be the most uplifting.

Appendix 8

Demographic and neurological information

1. Age of female partner 20 - 30
31 - 40
41 - 50
51 - 60

Age of male partner 21 - 30
31 - 40
41 - 50
51 -60

2. Number of years couple have been together in a stable relationship

3. Children and their ages

4. Does anyone else live in the household?

5. Previous occupation of male

Current occupation

6. Previous occupation of female

Current occupation

7. Previous medical history

	Female	Male
Minor ailments only		
One major illness		
More than one major illness		

8. Previous psychiatric history

	Female	Male
None		
OP treatment		
IP treatment		

9. Number of months since head injury

10. Period of time spent unconscious

1 none
2 up to 24 hours
3 1 - 7 days
4 more than 7 days

11. Duration of PTA?

1 less than 24 hours
2 1 - 7 days
3 7 - 21 days
4 21- 28 days

12. Is the person physically mobile?

1 yes, independent
2 needs help (stick/crutch)
3 confined to wheelchair

13. Nature of the accident

1 RTA car driver
2 RTA motorcycle driver
3 RTA car passenger
4 RTA motorcycle passenger
5 RTA cyclist
6 RTA pedestrian
7 other

14. Circumstances of injury

15. Has the head injured person been receiving help from any of the following services:

OT
Physiotherapy
Speech therapy
Psychology
Psychiatry
Social services
Rehabilitation
Other (please specify)

16. How often does the head injured person visit his GP?

17. How often do you visit your GP?

18. Do you have any comments you would like to make about any services you have recieved?

19. Are you still waiting for any compensation claims (if applicable)?

Appendix 9

GENERAL HEALTH QUESTIONNAIRE (GHQ-12)

Name:..... **Date:** .....

Please read this carefully.

We should like to know if you have had any medical complaints and how your health has been in general, over the last few weeks. Please answer ALL the questions simply by underlining the answer which you think most nearly applies to you. Remember that we want to know about present and recent complaints, not those that you had in the past.

It is important that you try to answer ALL the questions.

Thank you very much for your co-operation.

Have you recently . . .

1. been able to concentrate on whatever you're doing?	Better than usual	Same as usual	Less than usual	Much less than usual
2. lost much sleep over worry?	Not at all	No more than usual	Rather more than usual	Much more than usual
3. felt that you are playing a useful part in things?	More so than usual	Same as usual	Less useful than usual	Much less useful
4. felt capable of making decisions about things?	More so than usual	Same as usual	Less so than usual	Much less than usual
5. felt constantly under strain?	Not at all	No more than usual	Rather more than usual	Much more than usual
6. felt you couldn't overcome your difficulties?	Not at all	No more than usual	Rather more than usual	Much more than usual
7. been able to enjoy your normal day-to-day activities?	More so than usual	Same as usual	Less so than usual	Much less than usual
8. been able to face up to your problems?	More so than usual	Same as usual	Less so than usual	Much less able
9. been feeling unhappy and depressed?	Not at all	No more than usual	Rather more than usual	Much more than usual
10. been losing confidence in yourself?	Not at all	No more than usual	Rather more than usual	Much more than usual
11. been thinking of yourself as a worthless person?	Not at all	No more than usual	Rather more than usual	Much more than usual
12. been feeling reasonably happy, all things considered?	More so than usual	About same as usual	Less so than usual	Much less than usual

Appendix 10

Instructions for completing Problem Checklist

The questionnaire I shall now ask you to complete is designed to give me an understanding of what sort of difficulties, in your opinion, your husband experiences.

Can you answer the questions according to how you think he has been over the past two months. This questionnaire has a number of statements describing different kinds of behaviour, mood difficulites and problems which people sometimes experience. Alongside each statement are four possible answers; if, in your opinion, he is never like this or only rarely, put a tick next to number 1. If he is like this sometimes, but not too frequently, put a tick next to number 2, and so on. For example, where the statement reads 'has trouble sleeping' , if he is sometimes bothered by this then you would put a tick by number 2.

Please read each of the statements and indicate how you think your husband has been.

	1 = almost never 2 = sometimes 3 = often 4 = almost always				
1	Has trouble sleeping	1....	2....	3....	4....
2	Has rapid mood changes	1....	2....	3....	4....
3	Has difficulty becoming interested in things	1....	2....	3....	4....
4	Uses a wheelchair	1....	2....	3....	4....
5	Does the same thing over & over again	1....	2....	3....	4....
6	Is generous towards others	1....	2....	3....	4....
7	Is restless	1....	2....	3....	4....
8	Has difficulty with hearing	1....	2....	3....	4....
9	Gets ideas stuck in his/her head	1....	2....	3....	4....
10	Is unreasonable	1....	2....	3....	4....
11	Repeats words & phrases	1....	2....	3....	4....
12	Cries easily	1....	2....	3....	4....
13	Loses balance	1....	2....	3....	4....
14	Is sexually disinhibited	1....	2....	3....	4....
15	Is confident	1....	2....	3....	4....
16	Is upset by changes in routine	1....	2....	3....	4....
17	Thinks only of him/herself	1....	2....	3....	4....
18	Feels anxious or worried	1....	2....	3....	4....
19	Behaves childishly	1....	2....	3....	4....
20	Has fits (seizures)	1....	2....	3....	4....
21	Is affectionate towards others	1....	2....	3....	4....
22	Is easily tired	1....	2....	3....	4....
23	Has few leisure interests	1....	2....	3....	4....
24	Is quick to lose his/her temper	1....	2....	3....	4....
25	Has difficulty engaging in sex	1....	2....	3....	4....
26	Has difficulty with seeing	1....	2....	3....	4....

	1 = almost never 2 = sometimes 3 = often 4 = almost always				
27	Is verbally aggressive	1....	2....	3....	4....
28	Is physically aggressive	1....	2....	3....	4....
29	Has memory difficulties	1....	2....	3....	4....
30	Is withdrawn	1....	2....	3....	4....
31	Is incontinent	1....	2....	3....	4....
32	Gets very sad, fed up	1....	2....	3....	4....
33	Is intolerant of others	1....	2....	3....	4....
34	Just sits	1....	2....	3....	4....
35	Feels people don't care about him/her	1....	2....	3....	4....
36	Walks unaided	1....	2....	3....	4....
37	Doesn't pick up social cues	1....	2....	3....	4....
38	Is suspicious/mistrustful of others	1....	2....	3....	4....
39	Feels depressed	1....	2....	3....	4....
40	Attends to personal hygiene	1....	2....	3....	4....
41	Is impulsive, acts without thought	1....	2....	3....	4....
42	Wants sex less often than before	1....	2....	3....	4....
43	Is irritable	1....	2....	3....	4....
44	Behaviour is socially inappropriate	1....	2....	3....	4....
45	Is lacking in initiative	1....	2....	3....	4....
46	Has difficulty organising activities	1....	2....	3....	4....
47	Gets stuck in middle of doing things	1....	2....	3....	4....
48	Talks of suicide	1....	2....	3....	4....
49	Seems to have no control over emotions	1....	2....	3....	4....
50	Is kind	1....	2....	3....	4....
51	Feels unwell	1....	2....	3....	4....
52	Needs a lot of attention	1....	2....	3....	4....

1 = almost never 2 = sometimes 3 = often 4 = almost always

53	Clumsy, bumping into things or dropping things	1....	2....	3....	4....
54	Seems disoriented or lost	1....	2....	3....	4....
55	Has difficulty with sense of taste or smell	1....	2....	3....	4....
56	Seems confused about things	1....	2....	3....	4....
57	Is insensitive to others	1....	2....	3....	4....
58	Feelings get hurt easily	1....	2....	3....	4....
59	Needs to keep things tidy	1....	2....	3....	4....
60	Behaves in odd ways	1....	2....	3....	4....
61	Expresses odd ideas	1....	2....	3....	4....
62	Feels unwanted	1....	2....	3....	4....
63	Has headaches	1....	2....	3....	4....
64	Laughs for no obvious reason	1....	2....	3....	4....
65	Has difficulty speaking	1....	2....	3....	4....
66	Has difficulty expressing thoughts	1....	2....	3....	4....
67	Has to be told what to do	1....	2....	3....	4....
68	Talks too much	1....	2....	3....	4....
69	Is dependable	1....	2....	3....	4....
70	Complains about people and things in general	1....	2....	3....	4....
71	Refuses to compromise	1....	2....	3....	4....
72	Has dizzy spells	1....	2....	3....	4....
73	Talks about being angry with certain people	1....	2....	3....	4....
74	Is responsible	1....	2....	3....	4....
75	Has difficulty concentrating	1....	2....	3....	4....
76	Other:.....	1....	2....	3....	4....

THE GOLOMBOK RUST INVENTORY OF MARITAL STATE (GRIMS)
QUESTIONNAIRE

Before beginning the questionnaire, please complete this section in block capitals

NAME: ..... SEX: .....

DATE: ..... AGE (Years): ..... LENGTH OF RELATIONSHIP: ..... Years ..... Months

NAME OF PARTNER: .....

Instructions

Each statement is followed by a series of possible responses: strongly disagree (SD), disagree (D), agree (A), strongly agree (SA). Read each statement carefully and decide which response best describes how you feel about your relationship with your partner; then circle the corresponding response.

Please respond to every statement: if none of the responses seem *completely* accurate, circle the one which you feel is *most* appropriate. Do not spend too long on each question.

Please answer this questionnaire without discussing any of the statements with your partner. In order for us to obtain valid information it is important for you to be as honest and as accurate as possible.

All information will be treated in the strictest confidence.

	Strongly disagree	Disagree	Agree	Strongly agree
1. My partner is usually sensitive to and aware of my needs	SD	D	A	SA
2. I really appreciate my partner's sense of humour	SD	D	A	SA
3. My partner doesn't seem to listen to me any more	SD	D	A	SA
4. My partner has never been disloyal to me	SD	D	A	SA
5. I would be willing to give up my friends if it meant saving our relationship.....	SD	D	A	SA
6. I am dissatisfied with our relationship	SD	D	A	SA
7. I wish my partner was not so lazy and didn't keep putting things off.....	SD	D	A	SA
8. I sometimes feel lonely even when I am with my partner	SD	D	A	SA
9. If my partner left me life would not be worth living	SD	D	A	SA
10. We can 'agree to disagree' with each other	SD	D	A	SA
11. It is useless carrying on with a marriage beyond a certain point.....	SD	D	A	SA
12. We both seem to like the same things	SD	D	A	SA
13. I find it difficult to show my partner that I am feeling affectionate	SD	D	A	SA
14. I never have second thoughts about our relationship	SD	D	A	SA
15. I enjoy just sitting and talking with my partner	SD	D	A	SA
16. I find the idea of spending the rest of my life with my partner rather boring	SD	D	A	SA
17. There is always plenty of 'give and take' in our relationship ..	SD	D	A	SA
18. We become competitive when we have to make decisions.....	SD	D	A	SA
19. I no longer feel I can really trust my partner.....	SD	D	A	SA
20. Our relationship is still full of joy and excitement	SD	D	A	SA
21. One of us is continually talking and the other is usually silent	SD	D	A	SA
22. Our relationship is continually evolving	SD	D	A	SA
23. Marriage is really more about security and money than about love	SD	D	A	SA
24. I wish there was more warmth and affection between us.....	SD	D	A	SA
25. I am totally committed to my relationship with my partner....	SD	D	A	SA
26. Our relationship is sometimes strained because my partner is always correcting me.....	SD	D	A	SA
27. I suspect we may be on the brink of separation	SD	D	A	SA
28. We can always make up quickly after an argument.....	SD	D	A	SA

THE GOLOMBOK RUST INVENTORY OF MARITAL STATE (GRIMS)
SCORE SHEET

NAME: ..... SEX: .....

DATE: ..... AGE (Years): ..... LENGTH OF RELATIONSHIP: ..... Years ..... Months

NAME OF PARTNER: .....

Raw score	
Transformed score	
Partner's raw score	
Partner's transformed score	

Table of Transformations and Interpretation

Raw score	Transformed score	Interpretation
47 or more	9	very severe problems
42 to 46	8	severe problems
38 to 41	7	bad
34 to 37	6	poor
30 to 33	5	average
26 to 29	4	above average
22 to 25	3	good
17 to 21	2	very good
16 or less	1	(undefined)

Comments

Name of therapist .....

ITEMS

1.	3	2	1	0
2.	3	2	1	0
3.	0	1	2	3
4.	3	2	1	0
5.	3	2	1	0
6.	0	1	2	3
7.	0	1	2	3
8.	0	1	2	3
9.	3	2	1	0
10.	3	2	1	0
11.	0	1	2	3
12.	3	2	1	0
13.	0	1	2	3
14.	3	2	1	0
15.	3	2	1	0
16.	0	1	2	3
17.	3	2	1	0
18.	0	1	2	3
19.	0	1	2	3
20.	3	2	1	0
21.	0	1	2	3
22.	3	2	1	0
23.	0	1	2	3
24.	0	1	2	3
25.	3	2	1	0
26.	0	1	2	3
27.	0	1	2	3
28.	3	2	1	0

Appendix 12

GRISS QUESTIONNAIRE (FEMALE)

PLEASE COMPLETE THIS SECTION IN BLOCK CAPITALS BEFORE BEGINNING THE QUESTIONNAIRE

DATE .....

NAME .....

.....

AGE ..... YEARS

NAME OF PARTNER .....

.....

LENGTH OF RELATIONSHIP:

..... YEARS ..... MONTHS

INSTRUCTIONS

Each question is followed by a series of possible answers:

N NEVER
H HARDLY EVER
O OCCASIONALLY
U USUALLY
A ALWAYS

Read each question carefully and decide which answer best describes the way things have been for you recently; then circle the corresponding letter.

PLEASE ANSWER EVERY QUESTION
If you are not completely sure which answer is most accurate, circle the answer which you feel is most appropriate.

Do not spend too long on each question.

Please answer this questionnaire without discussing any of the questions with your partner. In order for us to obtain valid information it is important for you to answer each question as honestly and as accurately as possible.

ALL THE INFORMATION WILL BE TREATED IN THE STRICTEST CONFIDENCE.

		NEVER	HARDLY EVER	OCCASIONALLY	USUALLY	ALWAYS
1	Do you feel uninterested in sex?	N	H	O	U	A
2	Do you ask your partner what he likes or dislikes about your sexual relationship?	N	H	O	U	A
3	Are there weeks in which you don't have sex at all?	N	H	O	U	A
4	Do you become easily sexually aroused?	N	H	O	U	A
5	Are you satisfied with the amount of time you and your partner spend on foreplay?	N	H	O	U	A
6	Do you find that your vagina is so tight that your partner's penis cannot enter it?	N	H	O	U	A
7	Do you try to avoid having sex with your partner?	N	H	O	U	A
8	Are you able to experience an orgasm with your partner?	N	H	O	U	A
9	Do you enjoy cuddling and caressing your partner's body?	N	H	O	U	A
10	Do you find your sexual relationship with your partner satisfactory?	N	H	O	U	A
11	Is it possible to insert your finger into your vagina without discomfort?	N	H	O	U	A
12	Do you dislike stroking and caressing your partner's penis?	N	H	O	U	A
13	Do you become tense and anxious when your partner wants to have sex?	N	H	O	U	A
14	Do you find it impossible to have an orgasm?	N	H	O	U	A
15	Do you have sexual intercourse more than twice a week?	N	H	O	U	A
16	Do you find it hard to tell your partner what you like and dislike about your sexual relationship?	N	H	O	U	A
17	Is it possible for your partner's penis to enter your vagina without discomfort?	N	H	O	U	A
18	Do you feel there is a lack of love and affection in your sexual relationship with your partner?	N	H	O	U	A
19	Do you enjoy having your genitals stroked and caressed by your partner?	N	H	O	U	A
20	Do you refuse to have sex with your partner?	N	H	O	U	A
21	Can you reach orgasm when your partner stimulates your clitoris during foreplay?	N	H	O	U	A
22	Do you feel dissatisfied with the amount of time your partner spends on intercourse itself?	N	H	O	U	A
23	Do you have feelings of disgust about what you do during lovemaking?	N	H	O	U	A
24	Do you find that your vagina is rather tight so that your partner's penis can't penetrate very far?	N	H	O	U	A
25	Do you dislike being cuddled and caressed by your partner?	N	H	O	U	A
26	Does your vagina become moist during lovemaking?	N	H	O	U	A
27	Do you enjoy having sexual intercourse with your partner?	N	H	O	U	A
28	Do you fail to reach orgasm during intercourse?	N	H	O	U	A

GRISS SCORING SHEET (FEMALE)

OVERALL SCORE

Raw Score

Transformed Score

DATE .....

NAME .....

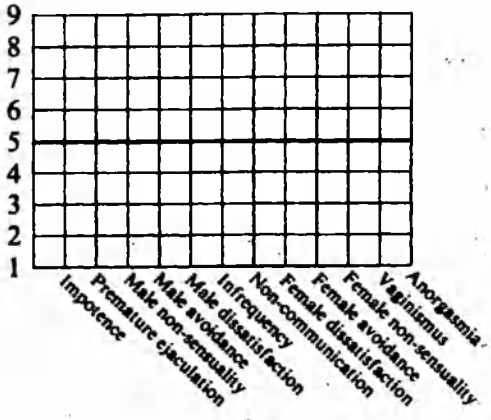
AGE ..... YEARS

NAME OF PARTNER .....

LENGTH OF RELATIONSHIP:

..... YEARS ..... MONTHS

PROFILE



INF Infrequency
NCO Non-communication
DISF Female dissatisfaction
AVF Female avoidance
NSF Female non-sensuality
VAG Vaginismus
ANORG Anorgasmia

TABLE OF SUBSCALE SCORES

INF		*NCO*		*DISF*		*AVF*		*NSF*		*VAG*		*ANORG*	
Item	Score	Item	Score	Item	Score	Item	Score	Item	Score	Item	Score	Item	Score
3		2		5		7		9		6		8	
15		16		10		13		12		11		14	
				18		20		19		17		21	
				22		23		25		24		28	
Raw Scores Total													
Transformed Total													

TABLE OF TRANSFORMATIONS

Transformed Score	Raw Overall Score	Raw Subscale Scores						
		INF	*NCO*	*DISF*	*AVF*	*NSF*	*VAG*	*ANORG*
9	68+	8	8	15, 16	12–16	11–16	13–16	16
8	60–67	7	7	14	10, 11	9, 10	11, 12	15
7	53–59	6	6	12, 13	8, 9	7, 8	8–10	14
6	46–52	5	5	10, 11	6, 7	5, 6	6, 7	12, 13
5	38–45	4	4	8, 9	4, 5	4	4, 5	9–11
4	31–37	3	3	6, 7	3	3	3	6–8
3	26–30	2	2	4, 5	2	2	2	4, 5
2	21–25	1	1	2, 3	1	1	1	1–3
1	0–20	0	0	0, 1	0	0	0	0

Item					
1	0	1	2	3	4
2	4	3	2	1	0
3	0	1	2	3	4
4	4	3	2	1	0
6	0	1	2	3	4
7	0	1	2	3	4
8	4	3	2	1	0
9	4	3	2	1	0
11	4	3	2	1	0
12	0	1	2	3	4
13	0	1	2	3	4
14	0	1	2	3	4
15	4	3	2	1	0
16	0	1	2	3	4
17	4	3	2	1	0
19	4	3	2	1	0
20	0	1	2	3	4
21	4	3	2	1	0
23	0	1	2	3	4
24	0	1	2	3	4
25	0	1	2	3	4
26	4	3	2	1	0
27	4	3	2	1	0
28	0	1	2	3	4

Published by The NFER-NELSON Publishing Company Ltd., Darville House, 2 Oxford Road East, Windsor, Berks. SL4 1DF.
Printed in Great Britain.
4041 04 4

Appendix 13

Aspects of sexual relationship questionnaire: 1 (before husband/ partner sustained head injury)

The following questions are of a personal nature. It would be helpful if you could try to answer them as accurately as you can in relation to how you felt in your relationship before your husband/partner sustained his head injury. Please circle the appropriate response:

N = never; H = hardly ever; O = occassionally; U = usually; A = always.

1. Did you find your sexual relationship with your partner satisfactory?	N H O U A
2. Did you feel there was a lack of love and and affection in your sexual relationship with you partner?	N H O U A
3. Did you ask your partner what he liked or disliked about your sexual relationship?	N H O U A
4. With regard to communicating your needs, did you find it hard to tell your partner what you liked and disliked about your sexual relationship?	N H O U A
5. Were there times when you tried to avoid having sex with your partner?	N H O U A
6. Were there times when you became tense and anxious when your partner wanted to have sex?	N H O U A
7. Were there times when you refused to have sex with your partner?	N H O U A
8. Did you enjoy having sex with your partner?	N H O U A

Appendix 13

Aspects of sexual relationship questionnaire: 2 (current relationship)

Here the same questions are presented except they are relation to how you feel about your relationship now. Again, it would be helpful if you could try to answer them as accurately as you can. Please circle the appropriate response:

N = never; H = hardly ever; O = occassionally; U = usually; A = always.

1. Do you find your sexual relationship with your partner satisfactory?	N H O U A
2. Do you feel there is a lack of love and and affection in your sexual relationship with you partner?	N H O U A
3. Do you ask your partner what he likes or dislikes about your sexual relationship?	N H O U A
4. Do you find it hard to tell your partner what you like and dislike about your sexual relationship?	N H O U A
5. Do you ever try to avoid having sex with your partner?	N H O U A
6. Do you become tense and anxious when your partner wants to have sex?	N H O U A
7. Do you refuse to have sex with your partner?	N H O U A
8. Do you enjoy having sex with your partner?	N H O U A

Appendix 14

Relationship Change Questions

Each of the statements below are followed by a series of possible responses:

yes, definitely; yes, sometimes; no not much; no, not at all;

Please read each statement carefully and decide which response best describes how true you believe each statement to be, then circle the corresponding response.

If none of the responses seem completely accurate then circle the one which you feel is most appropriate. Do not spend too long on each question. Please try to answer the questions as accurately as possible.

1. My partner has felt like a stranger to me since the injury.

yes, definitely; yes, sometimes; no not much; no, not at all;

2. My partner depends on me more since his injury than he used to.

yes, definitely; yes, sometimes; no not much; no, not at all;

3. My role within our relationship has changed a lot since the injury.

yes, definitely; yes, sometimes; no, not much; no, not at all;

4. My partner's sexual advances are welcomed by me most of the time.

yes, definitely; yes, sometimes; no, not much; no, not at all;

5. My partner's sexual advances sometimes feel coercive to me.

yes, definitely; yes, sometimes; no, not much; no, not at all;

6. My partner is just as interested in our sexual relationship now as he was before the injury.

yes, definitely; yes, somewhat; no, not so much; no, not at all;

Appendix 15

Relationship Questionnaire for men

Instructions

Each statement is followed by a series of possible responses: strongly agree, disagree, agree, strongly agree. Please read each statement carefully and decide which response best describes how you feel about your relationship with your partner/husband, then circle the corresponding response.

If none of the responses seem completely accurate then circle the one which you feel is most appropriate. Do not spend too long on each question. Please try to anwser the questions as accurately as possible.

1. We both seem to like the same things	strongly disagree	disagree	agree	strongly agree
2. I find it difficult to show my partner that I am feeling affectionate	strongly disagree	disagree	agree	strongly agree
3. I never have second thoughts about my relationship	strongly disagree	disagree	agree	strongly agree
4. I enjoy just sitting and talking with my partner	strongly disagree	disagree	agree	strongly agree
5. There is always plenty of give and take in our relationship	strongly disagree	disagree	agree	strongly agree
6. I wish there was more warmth and affection between us	strongly disagree	disagree	agree	strongly agree
7. I am totally committed to my relationship with my partner	strongly disagree	disagree	agree	strongly agree
8. We can always make up quickly after an argument	strongly disagree	disagree	agree	strongly agree

Appendix 16

Open questions

1. How would you describe the changes, if any, regarding your role/ position in your relationship since the injury?

2. What do you think are your perceptions of your partner's feelings for you?

3. What aspect of your relationship has changed the most since your partner's/husband's injury?

4. a) What opportunities have you been offered to explore these issues?

   b) Were they helpful?

   c) What else would you have liked, if anything?

5. a) How do you see the future?

   b) Do you have any specific plans?

6. What aspects of your relationship do you view as positive?

7. Is there anything else that you feel is important to add, or that you would like to say about your relationship since your partner's/husband's injury?

Appendix 17

End of visit questions

Thank you for taking part in this study. You may have found some of the questions evoked difficult feelings and I am concerned about how it felt for you to take part. To explore this further it would be helpful if you would answer the following questions.

1. How did it feel to participate in this study?

2. What feelings did it evoke for you?

3. Were there any questions you did not answer?

If yes, what was the reason for this
a) you did not know the answer
b) the question felt too intrusive
c) the question was difficult to understand
d) other, please specify if you can.

4. Is there anything you think should have been done differently?

If yes, what was it, and how do you suggest it might be done instead?

5. Would you like a standard letter sent to your GP saying that you have taken part in this study?

6. Would you like a follow up telephone call?

Appendix 18

Information on local services

1. Clinical psychology services (NHS)
Clinical psychologists, and sometimes also counsellors, work within these services. Generally, their aims are to help people find ways of coping with the problems which can arise when life stresses, thoughts, feelings and reactions cause distress. They are accessed through your GP who can make a referral. Waiting list times may vary across departments.

2. Headway, National Head Injury Association
This is an association of groups comprising head injured people, relatives and professionals. It aims to promote understanding of all aspects of head injury, to provide support, information and services to people with head injury, their families and carers.

Local branch tel.

3. Relate (previously known as Marriage Guidance)
This is a charity whose aims are to offer counselling and support to couples who identify problems wihin their relationships. The service does ask for a donation of whatever the couple can afford. People can refer themselves to this service; waiting lists may vary across branches.

Local branch tel.

4. Crossroads Carers Association
This is a charity which supports carers, providing volunteer sitters, carer's groups and support.

Local branch tel.

Appendix 19

Request for summary of findings

It is anticipated that a summary of the findings of this study will be available from August 1996. If you would like to receive a copy of this please complete the details below and return them by the end of August in the Freepost envelope.

Name

Address

Dr. Derek Steinberg
M.B., B.S., M.Phil., D.P.M., F.R.C. Psych

14 DEVONSHIRE STREET
LONDON
W1N 1PB
Telephone: 071-935 0640
Facsimile: 071-224 6256

Appendix 20

Correspondence, Appointments a
TICEHURST HOUSE HOSP
TICEHURST, NR WADHU
SUSSEX TN5 7HU
Telephone: (0580) 2003
Facsimile: (0580) 20100

PRIVATE AND CONFIDENTIAL 3rd January 1996

Dr Mike Oddy
Ticehurst House Hospital

Dear Mike,

Marital Couple Relationships and Emotional State following CHI - Dr Joanna Gosling

Further to my telephone message, many thanks for the revised proposal. I think my main concern was whether potential participants were aware of what they were getting involved in and this does now seem to be dealt with by the point made in the proposal that there will be a description of what participation will entail. I hope this would include the extent of the study (i.e. the numerous multi-item questionnaires to be completed) as well as the content. As long as participants are fully aware of all this before they agree to take part, I think there could be no ethical objection there.

On the issue of confidentiality (the second paragraph in my letter of 20.9.95), possibly I was more concerned about this than strictly necessary. The matter would first arise if a paper is published in a journal, and no doubt there will be the usual care re confidentiality at that point. However, the national press and other media might be interested in the report and I suggest that there may then be a need for further vigilance about confidentiality and privacy.

With these provisos then, speaking for myself, I would be happy with the proposal, and as said before am delighted that Joanna Gosling and yourself are pursuing this research. Please remember, though, that I am writing as Clinical Tutor and as a colleague, but that unfortunately we do not at the moment have a formally constituted Ethics (Research) Committee. I am hoping, however, that this may grow out of our newly developing Ethics Committee.

Please don't hesitate to get back to me about any further points or queries this letter might raise.

Yours sincerely,

Derek Steinberg
Consultant Psychiatrist and Clinical Tutor

cc: Dr Herb Etkin, Medical Director
Mrs Margaret Cudmore, General Manager

Salomons Centre
David Salomons Estate, Broomhill Road
Southborough, TUNBRIDGE WELLS
Kent TN3 0TG

Telephone: 01892 515152
Fax: 01892 539102

Our Ref: AL/LT/075
Direct Fax: 01892 518446
E-mail: tlavender@salomons.org.uk

SALOMONS CENTRE

16th February 1996

Ms J Gosling
Salomons Centre

Dear Jo,

Re: Research Dissertation - Marital couple relationship and emotional state following closed head injury.

Thank you for the Revised Proposal for your research which has taken account in full of the conditions detailed in the Ethics Panel Report. The changes mean that Full Approval is now given for the Project.

The Panel wish you well with the project and look forward to hearing about the outcome.

Yours sincerely,

Dr A Lavender
Chair
Ethics Panel

WEST KENT HEALTH AUTHORITY

Preston Hall, Aylesford
Kent ME20 7NJ
Tel 01622 710161
Fax 01622 719802

2 April 1996

Jo Gosling
Psychologist in Clinical Training
Flat 1
34, Ventnor Villas
HOVE
East Sussex, BR3 3DA

Dear Ms. Gosling,

MARITAL COUPLE RELATIONSHIP AND EMOTIONAL STATE FOLLOWING CLOSED HEAD INJURY

PROTOCOL NO. 9/96 (Please quote in all correspondence)

Thank you for submitting this project for consideration by the Tunbridge Wells Local Research Ethics Committee, which considered it on Friday 15th March 1996.

Ethical approval is offered subject to changes, which will need to be seen, and I would be grateful if you could send the revised items to Mrs. Sylvie Adames so urgent action can be taken. These changes are:

- The contact letter to subjects should indicate that active consent to participation is required, so that those individuals wishing to participate should return the slip in the free post envelope rather than those who wish to decline.

- On your letter to participants, we would like you to include your telephone number in the second sentence of the last paragraph so that it reads 'Please feel free to contact me (on .....) if you have any further queries'

Once these amendments have been confirmed in writing to Mrs. Sylvie Adames, formal approval will be issued.

Yours sincerely

S.H. Adcock

pp **T.G. WILLIAMS**
CHAIRMAN
TUNBRIDGE WELLS LOCAL RESEARCH ETHICS COMMITTEE

Appendix 23

Dear Mrs.....

Marital Couple Relationships and Emotional State Following Closed Head Injury.

I am writing to you a second time in connection with the above study. I would just like to check with you (as suggested by your non return of the 'no contact please' slip) that it is all right for me to telephone you to discuss the project in more detail. During that conversation you could let me know whether you would be able to take part in the study.

If it is still acceptable to you that I telephone you, I would be grateful if you would return the attached slip (Freepost envelope enclosed) to confirm this as soon as possible. Many thanks.

Yours sincerely,

Jo Gosling
Psychologist in Clinical Training with

Dr Michael Oddy
Consultant Neuropsychologist

WEST KENT HEALTH AUTHORITY

Preston Hall, Aylesford
Kent ME20 7NJ
Tel 01622 710161
Fax 01622 719802

16 April 1996

Jo Goslin
psychologist in Clinical Training
Flat 1
34, Ventnor Villas
HOVE
East Sussex, BR3 3DA

Dear Ms. Goslin,

MARITAL COUPLE RELATIONSHIP AND EMOTIONAL STATE FOLLOWING CLOSED HEAD INJURY

PROTOCOL NO. 996 **(Please quote in all correspondence)**

Thank you for submitting the amendments to the above protocol as rquested by the Tunbridge Wells Local Research Ethics Committee. We are happy for this study to be given ethical approval for you to commence within the Tunbridge Wells area.

It is your responsibility as the researcher who made the application to notify the Local Research Ethics Committee immediately you become aware of any information which could cast doubt upon the conduct, safety or an unintended outcome of the study for which approval was given

If there are amendments which, in your opinion or opinion of your colleagues, could alter radically the nature of the study for which approval was originally given, a revised protocol should be submitted to the Committee.

You will no doubt realise that whilst the Committee has given approval for the study on ethical grounds, it is still necessary for you to obtain approval from the relevant Clinical Directors or Chief Executive of the Trust in which the work will be done.

Members of the Committee would like to know the outcome of the study and therefore ask that a report or copy of results is sent to the Secretary in due course.

Yours sincerely

S.M. Adcock

pp **T.G. WILLIAMS**
CHAIRMAN
TUNBRIDGE WELLS LOCAL RESEARCH ETHICS COMMITTEE

TICEHURST HOUSE
HOSPITAL

Established 1792

HEAD INJURY REHABILITATION UNIT

3 May 1996

Ms Jo Gosling
Flat 1
34 Ventnor Villas
Hove
East Sussex
BN3 3DA

Dear Ms Gosling

Re: Research Project

I am happy for you to contact suitable past patients of our Head Injury Service for your research project. I should like to write an initial letter to these patients and their partners in order to introduce you. I wish you luck with your study.

Kind regards.

Yours sincerely

Dr Michael Oddy
Consultant Neuropsychologist &
Director of Head Injury Services

Ticehurst, Wadhurst, East Sussex TN5 7HU Tel: 01580 200391 Fax: 01580 201006
Libra Health Group
Libra Health Limited. Registered Office: Unsted Park, Munstead Heath, Godalming, Surrey GU7 1UW Registered in England No. 1355923
Directors: J. Priestley (Managing) D. Torbett R.D.C. Vaughan S.K. Beaumont M. Cudmore S. Richards K. Payne

Appendix 26

Qualitative Results Categories

1. *What aspect of your relationship has changed the most since CHI?*

Themes of loss throughout. For all but one spouse these were seen as negative and sad. Much shock and surprise expressed. Examples of quotes:

> "There's no one thing that's changed - it's all changed and affects us both every single day."
> "Everything has changed, he's a very different person now."
> "I was totally unprepared for the changes in our relationship"
> "Everything has changed there's no one thing that's changed at all."
> "P looks the same but he's very different and other people don't understand that. I was really struck when 2 weeks after the accident and P had come home, my 7 year old came up to where P was lying and said 'when's my Daddy coming home?' I told him 'he is him'. That said it all for me. It's like being married to a completely different person. If I'd met P after the accident I wouldn't have married him."

Categories and examples	No. times mentioned
1.He's totally dependent on me	6
"I'm now in the carer role and that's the way I see the relationship, with me as carer."	
2. I've lost an equal partner	6
"I used to like the way that he was an important person and now he isn't and I don't like that"	
"we're no longer an equal partnership - I feel like I've lost my best friend.".	
3. Aggressive/explosive temper	5
"He's very aggressive and had attacked me, the police wanted me to press charges but I couldn't do that coz he's my husband."	
"He's physically abused me, without being provoked he kicked me really hard and sent me into a glass table top.....it's as if he's got road rage and that's frightening but now I'd give as good as he gives me."	
4.Temper means I/m always on guard/	5
"treading on eggshells."	
"Also, I think related to that we kept having a go at one another; it was all very tense, almost expecting it."	

"unpredictable"

5.Stress and strain 14

Three women had what they described as a 'complete breakdown' within the first year post accident.

"uptight a lot of the time"

"I'm drinking now, I feel like I deserve it.. sought help for this."

"I find him so frustrating; I usually calm myself down before I respond to him."

"I find I just keep coping and I don't think I've ever really let go and had a good cry because I've had to be the strong one , I just keep going for the children. I know I put barriers up so I can stay strong."

"The physical side of caring I'm good at, but the emotional side is feeling much more of a challenge and more demanding - I'm caring for a baby now as well as for M and I I'm beginning to wonder where there's time for me. It's more complicated now because M is no longer number one: I see the baby as being more vulnerable and so has to be number one, M has since become a bit more 'demanding. My way of responding to these demands has made me much more stroppy, I'm not as placid as I used to be. We've had some real arguments over things that before I wouldn't have been bothered about."

"Things are likely to change more espeially as we'd like another baby and J is not very good with change. I'm beginning to feel a bit more selfish about my own needs now."

"I didn't know how to respond to his temper and I used to bit my tongue bottling everything up. Now I'm just angry back to him and that feels much better"

"I constantly have to be on the ball re; what he's up to, for example keeping the car keys from him when he thought he could drive; also sorting things out when he blew up the microwave. I always have to monitor how I can pre-empt what he might do in situations."

"I do feel quite resentful that I have to do so much but and I know M can't help it."

6. Partner unhappy about wife working 2

"He clockwatches all the time, even if Im 2 minutes late, as if he resents me going out to work. I'm not even having a good time going out to work, it's a boring job, but it's as if he doesn't like me doing it."

"It might be related to him not coping well when things aren't exactly routine, or that at least I can go out to work and he can't."

"He doesnt' like the fact that I go to work as the breadwinner, it's not how he

thinks things should be."

7. The emotional side feels badly damaged 5

' I really miss the intimacy and closeness. Suddenly we had no closeness, things we used to do like lying in bed, talking and reading the newspapers after making love have all gone. 'There are times when I'd just love to be swept off my feet and loved just for me especially when I've tucked the last child into bed at night,'

7. Much less comapanionship and sharing. 6

"I'm missing the fun and silliness we used to share."

"we used to be really good friends and that's different, the companionship has gone"

8. We're isolated as a couple now. 7

"we hardly have any friends"

"V has said things in his temper to upset people so we've fallen out with them."

9. People don't understand or make allowances 6

"you can't see what's wrong"

"it's a non visible disability and stigmatised"

10. Sexual side has had the biggest change 4

a) it's non-existent now
"I haven't even told my best friend about the lack of a sexual relationship because of the taboo around talking about sex. I have come to believe that you can be there for each other being emotionally close, without the sexual side, but that side would be nice. I think the frustration of not having sex adds pressure to our relationship.I don't want to get to 70 and not have felt that warmth and closeness again. I can see frustrations setting in."

"the sexual side has changed a lot, Perhaps it's just me, but P has what I call a 'difficulty in performing' and when things don't go right he gets extrememly upset, so it feels beter to avoid it. Also, because he's so dependent on me, I'm much more like a mother to him, it doesn't feel right that we have sex together. I know I'm not the only one that feels like that because we've just started a carers support group at Headway and when I mentioned that about three other women said they felt the same. It's really difficult to describe the changes you feel.

P looks the same but he's very different and other people don't understand that."

b) it's there but extremely boring 5

"But I also get frustrated cos it would be nice to have some passion '

"The change in our sexual relationship is probably the biggest change. It's no longer significant in our relationship as it was, but then again, we're at a different stage in our lives, so maybe that would have happened anyway, as a natural progression."

"Our sexual relationship is very different now, it's completely flat for me and I don't feel as I used to. I do enjoy sitting just having a cuddle but sex doesn't feel right. I think it might be related to me looking after him: he was so childlike and dependent on me that it didn't seem right that we had that sort of relationship."

c)he's much more persistent 3

"The pressure I feel under in relation to our sexual relationship feels in many ways more oppressive than if I were being constantly physically abused.

"The sexual relationship has changed. He gets so full of aggression and is so persistent: this went on for ages with him being verbally persistent and wanting to have sex with me and one night I just got really frightened and ran out of the house to a neighbour who I stayed with. The next day I got an injunction and ended up taking him to court. He's never actually raped me though. '

11. He's got no insight, doesn't realise what he can and can't do, nor empathy 7

12. I feel a lot stronger as aperson, I've had to grow up a lot. (some described this as a positive thing about the accident) 7

"when I met D. I had hardly any confidence in myself; he was very confident and looked after me. Now it's completely the opposite I do all the looking after and I'm much more confident"

Appendix 26

2. How would you describe the changes (if any) regarding your role/position in your relationship?

Categories and examples	No.of times mentioned
1. Role reversal	8
" It means we no longer have a sharing relationship." "We've swapped roles completely. I do everything now."	
2. I'm the breadwinner.	5
3. I take all the responsibility/ I'm in charge now	14
'he's very passive and doesn't initiate anything'	
'I used to be fairly passive in the relationship and bow down to M's judgments and decisions, but now I'm more dominant and take more responsibilities.'	
'All the decisions are mine, especially when it comes to money - P is hopeless with that. I carry all the responsibilities while P just drifts through life with it all being rosy for him. One of the questions on the questionnaire was abour being competetive about making decisions, well that's never the case for us because I make all the decisions anyway.'	
4. I've lost a husband and gained a child/dependency	7
" no time for me now"	
"constantly moving the goal posts so he can achieve a bit more, allowing him to take risks but at the same time trying to minimise the risks. There's a constant tension between allowing him to achieve more independence and not treating him like a child"	
"P is now like a spoilt child and wants instant gratification all the time despite whoever else is around. There's no time for me."	
"it's like having another child, he's very vulnerable and very sensitive." "He's often very childlike in that he's always trying to please."	
5. Lack of trust	6
"he believes he's capable of doing things he's not" " have to take charge of his drugs, he's accidently overdosed before"	
6. My role to motivate him now	4

Appendix 26

"The CHI has made him lose all his get up and go, all determination and motivation. I often feel like shaking him into action"

7. The decision making is all mine now 5

3. What do you think are your partner's feelings for you?

Categories and examples	No. of times mentioned
1. Very grateful	7

'In his more humble moments, he say things like "I don't know where I'd be without you", but I don't get those comments generally. So it's hard to know."

"He's extremely grateful and says "I don't know what I'd have done without you" a lot of the time."

"I know he's very grateful to me and this sounds awful to say but he puts little notes in cards to me at Xmas saying how he couldn't have got by without me. I wish he wouldn't do this 'cos it reminds me that he's dependent on me, I'm not entirely comfortable with me being in the strong role.'"

2. openly affectionate, verbally and physically 6

"he can swing from one thinf to another, affection and aggression, I get really confused by this."

"he's become more loving and caring to me," said by a woman who's total identity was defined by being in the caring role.

3. He never shows me any affection 4

"but he must love me in his own way"

"Sometimes, if pushed he'll make an effort at showing me he cares, birthdays, anniversaries etc, but on the whole he doesn't communicate his feelings to me."

4. ' I dont' know what his feelings are for me - it's difficult to say' 5

"sometimes I think he wouldn't be bothered if I wasn't here"

5. 'I think he loves me' 4

Appendix 26

"I assume he's happy with me. He never communicates that he's not happy. We were never a couple that was all gushy with one another or went out holding hands, all lovey dovey. We've just never been that way."

6. He blames me for all the misery in his life and says I'm causing trouble 1

"I get very confused cos I know he loves me and is committed."

7.He still feels the same, for him it's as if nothing has changed. 2

8. He's constantly worried about doing the right thing to keep me happy 1

" which can feel a bit suffocating. He sometimes gets it wrong though. I think his self-esteem is low that if he's doing something for me that makes him feel a bit better."

Appendix 26

4. What aspects of your relationship do you view as positive?

1. Silence followed by 'that's very difficult to say' 6

'None' 1

"I don't really think about things like that - things are ticking over okay"

2. A sense of committment 6

"We've got this far and have moved forward. We've since got married (engaged at time of accident) and have had a baby, we have a nice home and are financially secure, which many young people starting off in life don't have."

3. Companionship/friendship 7

"we still do a lot together'
'we still care for each other'
we still share a sense of humour'
'on his good day s we get on quite well together

"We've begun to get some enjoyment from doing things together which we haven't had for ages."

"Also he's arranged a trip away for both of us that is especially meaningful to me and for him to do that when he wasn't even that keen on going himself means a lot to me. This time last year he would'nt have been able to do that; he didn't even have the confidence to ring for a taxi.

4. Good communication 2

5. Reliable 1

"I can trust him, he's very tolerant and stable. I can rely on him, he's just the opposite of how my father was."

"He never says anything nasty to me , but I suppose he under mines me by not giving me compliments."

7. There's nothing left for me.

'I think of leaving but I feel guilty for even thinking"

" Apart from committment, nothing" 1

5.How do you see the future?

Categories and examples	No. of times mentioned
1. Very uncertain	4
" think about being alone but I've never acted upon it "	
"Sometimes I just don't want to, sometimes I can see light at the end of the tunnel but often the curtains are drawn. I'm 25, and I've got no kids I'm not married and I wonder if I'll ever get those things. I think I block out what lies ahead, I can only hope that there's happiness for us both whether we're together or apart."	
"Sometimes I go to bed hating him and ask myself 'why am I here?' but then I think he needs me and where would he be without me. I've got this far with him, I don't know what Id do if we split up and I'd wasted all this time and energy on him. I think I'd be suicidal because of all that I've given."	
I have my doubts	
2. With dread	3
"I think to myself "do you want this for the rest of your life?" If they're happy then you are but if they're being shitty, then you feel that way too. So it depends on what your mood is at the time: if you're low then the future seems quite bleak, if you're a bit happier then it's rosier." 'Pretty bleak really. '	
3. That's very difficult to answer	3
4 Just take one day at a time	2
5. Sad	1
"I feel very sad about the future and also for D. He had just got his degree (mature student) 2 weeks before the accident - that's all been wasted. Although D's not really aware of this."	
6. I hope the children will come out of it sane	3
7. Little change	8
'As it's all hard work'	
I expect things will continue to be a one person show with the usual money worries.'	
'I'll just carry on being the breadwinner'	

8. More difficult 1

> "I can see the tensions building up and the increaisng demands making life busier. especially if we just want an ordinary family life. There will always be extra demands on me requiring a lot more effort just for an ordinary life."

9. I hope it's going to get better. 1

6. How did it feel to take part in the research?

Categories and examples	No.of times mentioned
1.'Okay as I feel it's something worthwhile'	10

"Good because I feel it should be shouted loud and clear what head injuries are about. When I first got your letter I thought good, someone's looking at it from the women's point of view."

"When D came out of rehab, everything revolved around him - there's two players in this game. We had severe problems because of his unreasonableness. There needs to be much more for relatives."

2. Therapeutic/cathartic	11

'It's felt like a good release to let the feelings gush out "
'a relief, as I've bottle so much up.'
'we really got into reminiscing about it'

"No-body's really taken a proper interest in how I feel and what it's all been like for me."

"Its' been nice to be able talk about it. I used to just talk to my mum and my best friend. I find it helps to share it."

"Just to talk was really helpful, it helped me think out aloud and understand myself more."

"I've never told anyone all this (relationship problems) before, this is the first time but I've been glad to have been able to."

"It's been helpful as it's reminded me that things used to be worse financially and also in the way I felt about his tempers."

"I could have talked on and on. Personally, I think it's a positive thing to talk about it, also if it's helpful to someone else that makes me happy to help.

"It makes me feel better to talk about it."

3. Sad and reflective	8

'made me feel quite emotional,

"It still makes me upset to talk about the accident. It's taken M away from me and it's taken my face away from me. There's also a feeling of relief that neither of us were killed"

'I usually cope by sweeping things under the carpet, but that has to be my way of coping, because life goes on.'

It's made me think about how our relationship has changed, but then relationships probably change over time anyway.

4. Sobering 9

'Made me realise how much I've coped with"

'Reminded me of how much hard work it's all been; it's brought home how painful it's been. When you're too busy getting on with things you don't notice it -you just get on and do."

'I'm very aware that I'm often one step removed from the awfulness of it all.'

'It's reminded me of how seriously ill M has been and brought back a lot of memories, but I don't think it hurts to remember things and it's important to keep things in context. Sometimes I just keep going in a way that feels like I've just got used to things being as they are without remembering what we've been'

"Answering the questionnaires was not easy beacuse I was confronted with things which I would like to have been able to answer more positively and I had to try and be honest with myself and answer as things really are."

5.It's made me realise that no-one's been interested in what the accident has done to me or to our relationship' 1

6. Difficult answering the more personal questions but I answered them all 3
'but I've always found these things difficult'

7. What opportunities for help/support through statutory services?

Categories and examples	No. of times mentioned
1. None	14
'None for the emotional side or for support. '	
2. Took selves to Relate found not to be helpful	3
3. Chose not to use Headway, where some support would have been available	2
4. Psychology	1

a) What would you have liked?

1. Family therapy	2
2. Long-term help for self	6
3. Don't know	4
4.It would be nice to have someone's ear	2

'to talk about particular situations and stresses as a release valve for me. I've got good family support but I don't like to bother them too much. I'd like some sort of informal support as this could help me avoid blowing a fuse and help me handle situations differently. My needs are much more on the emotional side now. '

"someone to talk to".

5. More information	6

b) services in acute phase?

1. Had to get stroppy to get what we wanted

In the acute service I feel M only got what he did in the end coz I was stroppy and made such a fuss to make sure he got what I felt he should have had; I was very insistent and I wonder how many

people end up not getting what they should have and are now really struggling because they're not articulate or insistent.

'Unless I'd really fought for services in the early days D wouldn't have got the hep he needed I really had to scream out. Luckily I knew the system, but there must be so many people that fall through the net and get inappropriate services. I'm positive D would be in a wheelchair now if it wasn't for me shouting about physio.

2. Betrayed/let down

'We've found there's's been a complete lack of services. We only ever saw a social worker coz a friend of mine had a friend who was a social worker. We feel betrayed by the lack of services.'

There should be more support and services in general; there was no-one available to talk to if I had wanted that.

'It felt like the rehab services didn't make me feel a part of what was going on, I felt alienated and uninvolved and yet at the end of the day it's me that's stuck with this changed person. I often did not know what was going on or what he was doing in rehab. '

'I felt the psychologists in the rehab services were unrealistic in thinking that more services would be available to me locally than there actually were. I felt communication was poor between the rehab services and GP, this is important coz life goes on for us after rehab and we're still in need.'

Other?

The accident has damaged my confidence and I don't trust anyone anymore - I'm so used to people making promises about what they'll do and never keeping them.

I've coped completely unsupported, ever since the injury. I always felt jealous every time P was offered support and help cos I wasn't getting any - p would be taken out for the day and I used to think what about me?. I was stuck having to cope with the kids, the housework and everything else.

Poverty

I've felt very angry that my like has been thrown into turmoil. It was a nightmare when injury happened, it puy us into a financial mess - if it hadn't been for my mother there'd have been some weeks go by that we wouldn't have had food.The poverty has been one of the biggest strains for me, D had no idea of what it was like.

I'd really recommend to other people in my situation to get help on an individual basis, although even picking the phone up to arrange it was a big step and that was difficult. It does help. Or self-help groups which I've tried, do help you to feel less isolated.

Appendix 27

Findings of inter-rater reliability on qualitative data

1. What aspect of your relationship has changed the most since your husband's injury?

The main themes found by the independent rater were 100 per cent concordant with those found by the author.

Author	Independent rater
Loss of partner	Loss of partner
Husband's mood swings	Husband's mood swings
Strain and distress of wives	Strain and distress of wives
Isolation and feeling stigmatised	Feeling stigmatised
Change in emotional and sexual relationship	Sexual relationship

The categories found by the independent rater were less in number than those found by the author, but those identified were found to occur almost as frequently by the independent rater. Changes in sexual relationship was found to occur more frequently by the independent rater because when this topic emerged during other parts of the interview, the response was counted under this heading.

Categories	Author	Independent rater
Strain from putting up with things	9	9
Isolation	7	
Wife a stronger person	7	7
Husband's lack of insight	7	
Husband's total dependency	6	
Loss of an equal partner	6	6
Loss of a close companion	6	
Feeling stigmatised	6	5
Husband's aggression	5	4
Wife 'on guard'	5	
Emotional side badly damaged	5	
Changes in sexual relationship	12	12

2. How would you describe the changes, if any, in your role in your relationship?

The main themes found by the independent rater were 100 per cent concordant with those found by the author.

Author	Independent rater

Appendix 27

Parental role	Being a mother
Decision making	Decision making/increased responsibility

The categories found by the independent rater were only slightly different from those found by the author.

Categories	Author	Independent rater
Total responsibility	14	13
Role reversal	8	
Lost a husband, gained a child	7	10 (included statemtents about being a mother)
Unable to trust him	6	
Being the breadwinner	5	5
Down to me to motivate him	4	5

3. What do you think are your partner's feelings for you?

The main themes found by the independent rater were almost identical to those found by the author.

Author	Independent rater
Husband's feelings of uncertainty	Lack of expression and uncertainty
Husband's feelings of gratitude	Gratitude
Husband's feelings of affection	He still loves me

The categories found by the independent rater were only slightly different from those found by the author.

Categories	Author	Independent rater
Full of gratitude	7	7
Openly affectionate	6	
Don't know what his feelings are	5	7
Never shows me any affection	4	5
I think he loves me	4	12 (included positive feelings expressed by husband)
He thinks nothing has changed	2	2
He blames me for all the misery in his life	1	
He's always anxious to make me happy	1	

4. What aspects of your relationship do you view as positive?

The main themes found by the independent rater were almost identical to those found by the author.

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Author	Independent rater
Committment	Security
Companionship	Friendship/mutual care/affection
Ambivalence	Not sure

The categories found by the independent rater were identical to those found by the author.

Categories	Author	Independent rater
Companionship	7	9 (includes good communication)
Committment	6	6
Good communication	2	
Reliable	1	

5. How do you see the future?

The main themes found by the independent rater were almost identical to those found by the author.

Author	Independent rater
Realistic	Expecting little/no change
Uncertainty/denial	Uncertain/live for today

The categories found by the independent rater were only slightly different from those found by the author.

Categories	Author	Independent rater
Little	9	10
Uncertain	4	6 (includes difficulty in answering question)
Question difficult to answer	3	
With dread	3	3
Hoping children will stay sane	3	3
Taking one day at a time	2	2
Sad	1	
Hoping for improvement	1	1
Getting more difficult	1	1

6. What opportunities have you had for help or support through statutary services?

Themes found by the independent rater were the same as those found by the author: had no help; and wanted help.

Where similar categories were found the number of times they occured was:

Appendix 27

Categories	Author	Independent rater
Offered no formal support	14	9
Self-referral to Relate	3	4 (includes psychological help)
Psychology	1	
Awaiting psychology appointment	1	

7. What support would you have liked?

Themes that the author found were that most women would have liked help of some kind; more information. The independent rater's theme was that wives wanted help or support.

The number of categories found by the independent rater were less than those found by the author.

Categories	Author	Independent rater
Long term help (therapy or counselling)	6	8 (includes someone to listen to them)
Someone to listen to their side of things	2	
Family therapy	2	
Information	6	
Don't know	4	

8. How did it feel to take part in the research?

The theme that both the author and rater found was that it was therapeutic and led to participants reflecting on the changes that had occured over time since injury.

The number of times categories were found by the independent rater were very similar for the independent rater and the author.

Categories	Author	Independent rater
Okay as it's something worthwhile	16	16
Therapeutic	11	11
Sobering	9	
Sad and reflective	8	12
Made me realise how abandoned Ive been	1	4 (combined last two of author's categories)
A bit difficult to answer some questions	3	